

INTERNATIONAL LEADERSHIP FORUM FOR WOMEN WITH  
DISABILITIES: FINAL REPORT MAY 1998



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for Women with Disabilities: Final Report

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countries. In addition, DMP distributes the video Disabled  
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## Dedication

This volume is dedicated to all of the women warriors who could not be with us at the Forum but whose contributions to the cause should be noted. A few are listed here:

- Angela Perez, a staunch international advocate for women with disabilities
- Elizabeth Boggs and Rosemary Dybwad, who between them kept the international spotlight on the needs of people with intellectual impairments and their families for more than 40 years.

All three American leaders died in the period just preceding the Forum.





- Theresia Degener, LL.D. of Germany, prominent human rights lawyer and bioethics specialist, who was forced temporarily out of action by the birth of Emil;
- Cheryl Marie Wade, U.S. performance artist, poet and editor of the online Gnarlybone News, who was seriously overbooked;
- Barbro Carlsson, long established Swedish disability rights champion, who had a family emergency; and
- Teresa Selli Serra, Ph.D. of Italy, author of the first UN Statement on women and disability (1975).

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Message from the Honorary Chair

The White House  
Washington  
June 15, 1997

Dear Friends:

As I have traveled around the world, I have seen first-hand that investing in girls and women helps to transform communities which in turn can transform societies.

While no single social investment is a panacea for women or for developing countries, I do believe that as long as discrimination and inequities persist in a broad-scale way against women, a stable, prosperous world will be far from reality. This especially holds true for women with disabilities. I am thankful for your commitment to providing a voice for those with disabilities. It is my hope that your efforts will inspire communities across the country and the world to follow your example.

Sincerely yours,

Hillary Rodham Clinton  
U.S. First Lady

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Dear Colleagues:

We extend our sincere appreciation to you for your part in making the 1997 International Leadership Forum for Women with Disabilities, such a rousing success. The comments have been overwhelmingly positive and it is gratifying that the first-ever international public/non-governmental/private partnership has proven to be a viable model for such global cooperation in the future.

As you may know, although originally planned for 300-400 participants, the Forum actually attracted 614 women from 80 countries and territories - a strong indication of the importance and the need these women attached to such a conference. And, even though the higher than expected attendance caused some logistical strains, they were cheerfully overlooked because of the substantive nature of the plenaries and workshops.

The hope was expressed by many participants that another country will take up the challenge and organize and host the next Forum in two years. In the meantime, the avenues of



communications will be kept open through networks established by the participants. We hope the Forum videos and this final report, contribute to the information exchange and look forward to hearing reports of your progress on behalf of women with disabilities.

Judith E. Heumann, M.P.H.  
Assistant Secretary,  
Office of Special Education and Rehabilitative Services  
U.S. Department of Education

Susan M. Daniels, Ph.D.  
Deputy Commissioner,  
Disability and Income Security Programs  
U.S. Social Security Administration

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## United Nations

The United Nations' concern with the rights of women with disabilities is rooted in the fundamental belief in, and the commitment to, equality between men and women in the equal enjoyment of all human rights enshrined in the Charter of the Organization, as well as in other United Nations human rights and policy instruments. The Organization's efforts are dedicated to advancement of the rights of disabled women for an independent life as full-fledged citizens, who contribute to their society through their talents and experience.

The International Leadership Forum for Women with Disabilities focused on education, health, employment, communications, policy, development, and legislative issues and their implications for training trainers for leadership development. It has informed, engaged and empowered disabled women from developing countries to participate on the basis of equality in the development of the communities in which they live, as well as to assume leadership roles in the policy dialogue on issues which affect their livelihood and well-being and that of their families and their communities.

The Forum for Women with Disabilities represented direct and practical follow-up to policy priorities of the following international instruments concerning the situation of the people with disabilities; the World Program of Action concerning Disabled Persons and the Standard Rules of Equalization of Opportunities for Persons with Disabilities, the Copenhagen Program of Action of the World Summit for Social Development, and the Beijing Platform for Action of the Fourth World Conference of Women.

John Langmore  
Director, Division of Social Policy and Development

## International Labour Organization

In ILO's continuing efforts to promote equality of opportunity and treatment for women and men in the world of work, women with disabilities is singled out as a particularly vulnerable group that needs special support. Therefore, the ILO Vocational Rehabilitation Branch is currently expanding its program to carry out research, technical advisory services, policy advice and awareness raising activities to ensure that women with disabilities have better access to training, employment and work. The objective is to "mainstream" or fully integrate the needs of women with disabilities into all these activities. ILO is





moreover using the International Labor Standards as tools to fight discrimination against women with disabilities in the labor force.

ILO's technical contribution and sponsorship of 26 participants in the Forum was a way to demonstrate the organization's commitment to support the rights of women with disabilities to work and income, as well as contribute to their societies. The ILO contribution also forms part of a concrete follow-up on the Beijing Platform of Action's request to international organizations to support and assist in opening the doors for women with disabilities to achieve leadership positions in the world of work.

Gabriele Stoikov  
Chief, Vocational Rehabilitation Branch  
International Labour Organization

#### Rehabilitation International

Rehabilitation International was proud to join in the unique partnership which resulted in this outstanding event of 1997. Now, we need to press forward together against the combined weight of cultural restrictions, gender-based violence and archaic attitudes which prevent the access of disabled girls and women to education, employment and adult roles in their communities.

Inspired by the many reports of both problems and progress by the 600 Forum participants, RI moved quickly to establish a Task Force on Women and Girls, ratified by its Assembly, meeting in Korea in September 1997. Co-chaired by disabled women leaders from Australia and Brazil, the Task Force is now building a diverse membership in order to develop programs working directly with the grassroots in interested countries. It will focus on locating support for projects that encourage mentoring and training opportunities, and which document "best practices" in measurably improving the situation of girls and women with disabilities. Task Force membership, regardless of organizational affiliation, is geared toward leaders who want to continue the collaborative approach which proved so successful with the Forum.

In 1998 RI staff and Task Force members are working with other disability organizations to: influence the UN Commission on the Status of Women to include women with disabilities within their priorities, expand public awareness through targeted dissemination of the Forum videos, and provide regional opportunities for disabled women and their allies to network at RI conferences taking place in Hong Kong and Jerusalem. We will most warmly welcome your participation in any or all of these initiatives.

Susan Parker  
Secretary General  
Rehabilitation International  
Disabled Peoples' International

The International Leadership Forum for Women with Disabilities had a great significance for the DPI Women's Committee and many other women around the world. This Forum was a demonstration of how women with disabilities overcame barriers, and traveled across the continents to meet together in Washington D.C., and unified their voices as one.

It was also a unique opportunity for women with disabilities and non-disabled women from diverse communities to analyze and compare their common situations in life; sometimes successful experiences, but most the time experiences of isolation and neglect. The Forum's plenary sessions and workshops were a great source of knowledge, information and inspiration for all participants.

DPI was very proud that so many of our delegates were able



to attend this important event. The legacy and inspiration obtained from the Leadership Forum will remain alive among the women the who participated. For DPI, the most important outcome is that the Women's Committee was recharged with energy and has set a long term agenda to continue the spirit of vitality and strength to follow our quest for equal opportunity and inclusion in a society for all.

At DPI, once again, we want to congratulate the International Leadership Forum organizers for their excellent work in planning and organizing this important event. We also deeply appreciate the sponsors support for making this event possible-- an event that will remain in the memories of hundreds of women with disabilities worldwide.

Lucy Hernandez Wong  
Executive Director  
Disabled Peoples' International

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### Story of the Forum

Some of us met for the first time in 1995 to press the disability agenda forward amidst the challenging circumstances of the UN 4th World Conference on Women and associated NGO Forum in China. Research interviews conducted there showed widespread, grassroots need for an international event to provide leadership training, networking and exchange of practical information on projects to benefit disabled women and girls. Disabled women leaders from around the world also wanted an opportunity to plan national strategies for follow-up to the Beijing Platform for Action.

In early 1996 staff of the World Institute on Disability, Rehabilitation International and Mobility International USA, using the resources of their joint grant (The U.S. National Institute for Disability and Rehabilitation Research/ International Disability Exchanges and Studies --IDEAS 2000), began looking for partners. The magnitude of results, achieved largely through the dynamic efforts of the Forum Co-Chairs, Judy Heumann and Susan Daniels, is illustrated by the list of sponsors elsewhere in this volume. More than 100 scholarships were provided to disabled women through the combined generosity of the International Labor Organization, the U.S. Information Agency and Agency for International Development and the United Nations, as well as other international groups and numerous private sponsors.

### The Results

Everyday I hear from someone whose life was changed by the Forum or about an organization whose batteries were recharged there. By all reports, the Forum was a smashing success and the historical event we hoped it would be.

Our Forum Final Statement has already been used in various meetings and conferences throughout the world, drawing attention to our priorities and our insistence that they be taken seriously. The Seoul International Disability Conference reserved a day for sessions on disabled women and the associated meeting of the UN Economic & Social Council for Asia & the Pacific (ESCAP) adopted a statement recognizing our concerns, following lobbying from Forum organizers. The ILO consultation on disabled women in late 1997 involved several Forum contributors.

### The Future

So far, we have been informed of the following follow-up initiatives for 1998: an international symposium on microcredit





for disabled women to be organized by MIUSA; special sessions of the DPI World Congress in Mexico City and the RI regional conferences in Hong Kong and Jerusalem; and a possible collaboration of the U.S. Departments of Education and Social Security to provide regional and domestic meetings for young disabled women on employment and leadership skills.

Hopefully, the Forum has been a significant step in empowering ourselves and in building networks and unity to improve the quality of life for disabled women all over the world. We ask that you keep the network alive and growing by informing us of any national, regional or international initiative to benefit disabled women and girls.

Kathy Martinez  
Director, International Division  
World Institute on Disability

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Dear Readers:

As one of the event products, this volume is comprised of reports and selected papers of the International Leadership Forum for Women with Disabilities, held 15-20 June 1997 in Washington, DC, USA.

Taking into consideration the enormous amount of information and number of presentations throughout the intense agenda of the Forum and the impossibility of publishing all of them, papers for this document were selected on the basis of two main criteria:

- if they contributed substantively to producing a portrait of the situation of disabled women and related initiatives worldwide; or
- if they provided concrete information and guidance on the implementation of policy and research to advance the status of women with disabilities.

Additionally, we were biased towards papers describing activities in developing countries or areas where little is known about women with disabilities. The papers have been edited for clarity and space, but each remains the viewpoint of the author.

We are pleased to include an Executive Summary of the research and evaluation conducted during the Forum by Tanis Doe, Ph.D. . To order her full report, please see page 187.

Supported by the U.S. National Institute for Disability and Rehabilitation Research, the evaluation report analyzes reactions of participants to Forum program and activities, while the research report summarizes the myriad of focus groups and interviews on aspects of leadership development held during the Forum. We believe the data and information in these reports can provide important guidance to those organizing future projects or carrying out research concerning women with disabilities.

This volume is also being produced in Braille, large print, audiotape and is available on disc. For a list of other Forum products, including videos, a disc of addresses of Forum participants, and associated reports, please see page 187.

Barbara Duncan & Rosangela Berman-Bieler  
March 15, 1998

Foreword from the Forum Director

Dear Sir,

As one of the most prominent and active in the field of research and development in the chemical industry, I am sure that you will be interested in the work of the Chemical Research Council, which is now in the process of being re-organized. The Council is a body of experts in the various branches of chemistry, and its main object is to promote research in the chemical sciences, and to disseminate the results of such research. The Council is now in the process of being re-organized, and its new structure is being put into effect. The new structure will be more efficient and more effective than the old one, and it will be able to carry out its work more successfully than ever before. I am sure that you will be interested in the work of the Council, and I am sure that you will be able to help it in its work. I am sure that you will be able to help it in its work, and I am sure that you will be able to help it in its work.

Yours faithfully,  
Sir

Enclosed find the report of the Council.

## Story of the Forum

Some of us met for the first time in 1995 to press the disability agenda forward amidst the challenging circumstances of the UN 4th World Conference on Women and associated NGO Forum in China. Research interviews conducted there showed widespread, grassroots need for an international event to provide leadership training, networking and exchange of practical information on projects to benefit disabled women and girls. Disabled women leaders from around the world also wanted an opportunity to plan national strategies for follow-up to the Beijing Platform for Action.

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Kathy Martinez  
Director, International Division  
World Institute on Disability

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The purpose of this study is to investigate the effects of the proposed changes on the system. The study is divided into two main parts: a theoretical analysis and an empirical study. The theoretical analysis is based on the principles of the proposed changes, while the empirical study is based on the results of the experiments.

2. Objectives

The objectives of this study are to:

- 1. Determine the effects of the proposed changes on the system.
- 2. Compare the results of the proposed changes with the results of the existing system.
- 3. Identify the strengths and weaknesses of the proposed changes.

3. Scope

The scope of this study is limited to the proposed changes and the results of the experiments. The study does not cover the entire system, but only the parts that are affected by the proposed changes.

4. Methodology

The methodology of this study is based on the principles of the proposed changes and the results of the experiments. The study is divided into two main parts: a theoretical analysis and an empirical study.

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International Leadership Forum Brings together Women From 80 Countries to Report on Progress & Strengthen Networks

The International Leadership Forum for Women with Disabilities was one of the most heralded, far reaching and successful events of 1997. Held June 15-20 in Washington, DC, the Forum attracted legislators, artists, advocates, organizational executives, trainers, international assistance experts and grassroots development specialists from around the globe. It was a success by all measures:

All the world's cultures and regions were well represented in the group of 612 participants from 82 countries and territories;

As a follow-up to the United Nations 4th World Conference on Women held in Beijing in 1995, the Forum served as an international progress report on concrete implementations of the Beijing Platform for Action benefiting the world's estimated 300 million disabled women and girls;

The Forum was the highest level event ever held that focused on the needs and achievements of disabled girls and women, attracting the participation of four U.S. Cabinet members, sponsorship of two United Nations agencies and three international organizations, and the support of more than 20 U.S. government departments and more than 20 corporate and non-profit organizations. Held under the Honorary Chairmanship of U.S. First Lady Hillary Rodham Clinton, the Forum received a letter of support from President of Ireland Mary Robinson and was addressed by Parliament members from South Africa, Finland, Tanzania and Uganda.

More than 50 training workshops, ranging from proposal writing to building wheelchairs, to using the Internet, to grassroots organizing were held.

Working through consensus, the Forum adopted a comprehensive closing statement outlining specific actions that need to be taken on international, national and grassroots levels to improve the situation of disabled girls and women in critical areas such as education, health services, employment and access to family and community life. The statement also demands actions to



eliminate all forms of violence and discrimination against girls and women with disabilities.

Sponsored by the U.S. Department of Education's Institute for Disability & Rehabilitation Research, the Forum featured several research initiatives which engaged the participants in identification of priorities for future training and focus groups in areas such as education, violence, parenting, and development of role models and mentors.

Through a website and a dedicated team of volunteers provided by the NCR Corporation, the daily proceedings of the Forum were accessible to thousands of off-site participants via the Internet.

## Results

In addition to the Forum Final Statement identifying actions to be taken, the Forum delegates agreed that: international meetings to further the progress of disabled women should take place at least every other year, rotating from region to region.

The research conducted at the Forum identified five main areas for training, action and further investigation: 1) education; 2) economic empowerment; 3) ending violence against women; 4) access to health services; and 5) access to family life. Other issues identified by those interviewed that cut across all topics of concern included: 1) attitudes towards disabled people, especially women; 2) role models/mentors/peer education and the need for more visibility and connection among women with disabilities; and 3) networking and training in leadership.

## Program Highlights

### June 16: Aspects of Leadership

On, Monday, June 16 there was a palpable sense of excitement in the room as Secretary of State Madeleine Albright and Secretary of Health & Human Services Donna Shalala, both veterans of the Beijing Conference, addressed the Forum. Albright announced new policies governing U.S. foreign assistance programs which will place disability issues "prominently on our development agenda with governments that receive our aid." She also described new initiatives of the Department of State to train disabled individuals for foreign service and to make U.S. embassies throughout the world accessible. To resounding applause, Albright bluntly stated, "If we Americans can export our strategies for selling hamburgers, surely we can export our strategies for meeting the needs and benefiting from the skills and strengths of people with disabilities."

Secretary Shalala then delivered a heartfelt speech recalling why international actions, such as the Forum, are necessary: "Because when women with disabilities are denied access to fundamental rights and fundamental health care, including reproductive care, we need international action. When landmines, domestic abuse, genital mutilation and other forms of violence continue to tear at the lives of women around the globe, we need international action. And when prejudice, ignorance and other barriers stop women from getting the nutrition, physical activity and other tools they need to live full and healthy lives, we need international action."

Kathy Martinez of the World Institute on Disability, Forum Director, challenged participants to use the week productively and positively, spending no more than 10% of the time describing how grim their situations are, and spending 90% of the time in defining solutions and identifying programs of excellence.





Keynote presenters Maria Rantho, Member of Parliament, South Africa; Venus Ilagan, President of the Philippine Federation of Disabled People; and Petrona Sandoval, grassroots organizer from Nicaragua, then outlined the dynamic approaches disabled women are taking to improve their lives in Africa, Asia and Latin America.

The leadership theme was further developed by Laura Liswood, who presented her unique video of interviews with women heads of state and government from around the world. Each President or Prime Minister gave her own sharply honed insights on the challenges, strengths and singular qualities of women's leadership. Liswood summarized that the wisest among them counseled that the vision for change always progressed from the unimaginable to the impossible, to the inevitable.

June 17: Education & Development

On Tuesday, June 17 Secretary of Education Richard Riley and his Assistant Secretary for Special Education and Rehabilitative Services, Judith Heumann, reported on the recent Congressional re-authorization of the Individuals with Disabilities Education Act, which ensures that no child will be denied an education because someone thinks he or she can't learn. Riley emphasized that, "this law makes sure that every young person has the opportunity to get the skills in order to live independently."

Heumann, Co-Chair of the Forum, was concerned that other countries not repeat mistakes of the Western segregated education systems and instead should now work collaboratively to build accessibility and inclusion into their schools and universities and curricula. Marca Bristo, Chair of the U.S. National Council on Disability, reminded the participants how only 20 years ago when she and many of the women in the room were beginning their advocacy efforts, there was no recognition of gender issues in the disability field and how much they have achieved in the interim.

Development assistance experts Brigitta Andersson of Sweden and Yukiko Nakanishi of Japan presented powerful overviews of their experience with programs to assist disabled people in developing countries to build services and organizations. Each stressed the actions which needed to be taken to strengthen the access of disabled girls and women to education and self-sufficiency.

June 18: Health & Family

Wednesday, June 18 was focused on Health & Family Issues and keynotes were delivered by Mary O'Hagan, a mental health advocate from New Zealand, Drs. Lesbia Salarzano and Lyubov Popova, physically disabled physicians from Nicaragua and Russia, and Marsha Saxton, a bioethics and genetic issues specialist from the USA. They stressed that disabled women as a group were uniformly denied access to reproductive information, sex education, motherhood and decision-making about operations, procedures and research performed on them. Saxton, recalling her childhood in a hospital, concluded, "I wish I could go back in time and tell all the other disabled girls in the hospital about this conference, tell them that we will have the knowledge and power and connections and hope to offer each other someday."

A unique part of the program was the series of "Ask the Doctor" seminars held Wednesday evening, featuring panels of disabled and non-disabled female physicians from several countries responding to questions from the floor.

June 19: Employment

On Thursday, June 19 Susan Daniels, Deputy Commissioner for Disability and Income Security Programs, U.S. Social Security Administration and Co-Chair of the Forum, opened Employment day with a rousing speech about the arguments often advanced by



employers and business owners that "it is too expensive to accommodate people with disabilities." Her presentation emphasized the need to "challenge the obvious," illustrating how non-disabled people have expectations that their technological and everyday needs will be accommodated with chairs, lighting, microphones, etc., with no question of needing to justify the associated expenses. Pauline Winter of New Zealand then described her country's system of helping disabled people find jobs and training through a network of employment, as opposed to disability specialists. Evy Messell, International Labor Organization Senior Specialist on Disadvantaged Youth and Women, outlined the ILO program to support creation of job opportunities and income generation for disabled people, especially women, in developing countries. Workshops then provided opportunities for participants to exchange practical information about employment and income generating projects, including wheelchair building and making farming accessible.

#### June 20: Technology & Media

On Friday, June 20 the two themes were communication and technology. Keynotes were delivered by Rachel Hurst of England, Rina Gill of UNICEF/Bangladesh and Salma Maqbool of Pakistan on their projects and research to improve the image of people with disabilities in the mass media. The technology theme was ably developed by Katherine Seelman and Deborah Kaplan of the USA who emphasized the need for the government and advocacy groups to work closely and persuasively with industry to ensure that the new communication and information technology be designed and/or adapted to the needs of disabled people.

#### Other Forum Activities

Other activities that the participants reported back they had found particularly useful were:

- videos concerning women's issues, especially "Women World Leaders," presented by Laura Liswood, and those illustrating disabled women as successful entrepreneurs, parents and community leaders;

- regional caucuses for participants held in the evenings; and
- a visit to a technology superstore with a special discount for Forum participants.

The exhilaration and exuberance of the group, however, were most evident during Tuesday's Talent Night of dancers, comedians, singers, poets and performance artists, and during Thursday night's closing party featuring dance music from around the world. The Forum venue, the Hyatt Regency of Bethesda, added to the ambiance of the event by its provision of food from different regions of the world and by its constant attention to the needs of disabled participants.

The Forum was organized jointly by the World Institute on Disability, Rehabilitation International and Mobility International USA. International Sponsors included the United Nations, the International Labor Organization, Rehabilitation International and Disabled people's International. More than 20 U.S. government departments financially and programmatically supported the Forum, including the Departments of Education, Defense, State, Health & Human Services, Justice, Transportation, Labor, Agriculture, the U.S. Social Security Administration, the U.S. Information Agency and U.S. Agency for International Development. The National Council on Disability contributed crucial coordination and management services.

More than 25 private sector sponsors also contributed, including the Dole Foundation, Ms. Foundation, Very Special Arts,



Paralyzed Veterans of America, the ELA Foundation, NYNEX/Bell Atlantic, the U.S. Council for International Rehabilitation and the World Bank.

#### Information about Forum Follow-up

1) Follow-up actions to the Forum- Kathy Martinez, Director, International Division, World Institute on Disability, 510 16th Street, Oakland, CA 94612; Tel 510 251 4326; Fax 510 763 9494; e-mail kathy@wid.org

2) Forum products- Rosangela Berman-Bieler, President, Third Millennium Events, 711 Brent Road, Rockville, MD 20850; tel 301 838 3031; Fax 301 838 3029; e-mail RBBieler@aol.com

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International Leadership Forum for Women with Disabilities  
Washington, D.C., USA - June 15-20, 1997

We the 614 women from 80 countries around the world at the International Leadership Forum for Women with Disabilities in Washington on June 15-20, 1997, are deeply encouraged by the emerging strength in the empowerment of women and girls with disabilities. We hereby want to send signals to all our sisters and brothers in the disability and women's rights movements. This important process is meant to include the possibility of growth of each and every individual woman and girl with disabilities worldwide. Consequently, we need partnerships with women and men in all walks of life. Our issues are among the top priority concerns of all human development. We believe that several concrete actions and considerations must occur regarding United Nations conventions and policies. Of specific importance are:

the Convention on Elimination of All Forms of Discrimination Against Women (CEDAW)

the United Nations Convention on the Rights of the Child

the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

and the promises within the Platforms for Action from the United Nations conferences and summit meetings.

Especially we note that the positive effects of the 1995 Beijing Conference on Women are still vigorously ongoing. We want the Beijing Platform for Action to be fully realized. We also demand that our states ratify the conventions, removing any reservations and other barriers to implementation.

Women in solidarity must unite and call for the stopping of wars and civil conflicts. Women and girls especially suffer the illnesses of poverty in wars' aftermath. Decision makers in countries affected by wars and conflict must take full responsibility to rehabilitate girls and women. We state the following:

#### Human Rights & Violence

We demand that the message of disabled women and girls be heard clearly in all debates and policies concerning genetic engineering, bioethics, prosthetic design and human engineering such as cochlear implants, abortion on grounds of disability, assisted suicide, euthanasia and all eugenic practices.

Such issues vitally concern disabled women and men, and have the potential to violate our fundamental and universal rights. We demand that all violations stop. Further, we demand that women





with disabilities participate in all levels of debate and policy development regarding reproductive research policies and programs.

We urgently raise our concern to our governments about the the UN Educational, Scientific and Cultural Organization (UNESCO) draft of a Universal Declaration on the Human Genome and Human Rights to be finalized in July, 1997. We question the wisdom of the draft text in respect to the human rights of disabled persons. We recommend that the governments discuss the draft text with the organizations of and for disabled persons in their countries.

We urge that international and national governmental and non-governmental organizations recognize the high rate of violence against disabled women and girls as a critical health and human rights issue in policy and legislation. Legal enforcement of assault and sexual abuse laws should be strengthened, including severe punishment of offenders and support for victims throughout the justice system.

We cannot accept that family members, paid and volunteer care givers, institutional staff, police, and even friends, are humiliating, assaulting, raping, exploiting, neglecting, forcibly isolating, withholding assistance, medical care or supports, abandoning, disposing of, putting out to beg, selling and even killing, women and girls with disabilities at alarming rates. Disabled children of battered mothers are particularly vulnerable to abuse. We urge that effective support be developed for victims and family members.

We request that the UN Special Rapporteur on Violence against women address violence against women and girls with disabilities as a pressing issue, in full cooperation with women with disabilities and their organizations. We request that disability organizations include the issue of violence among their priority concerns. We request the world's women's movement acknowledge the vicious insults visited upon women and girls with disabilities the world over, and take steps to improve solidarity among all women.

We demand immediate action to build access to information and services to escape, heal and survive abuse, all steps to preventing future cycles of violence.

We protest in solidarity with disabled women in all countries, where:

- 1) laws currently allow legal abortion only for the protection of the mother's health,
- 2) in the case of pressing economic circumstances, and,
- 3) in cases where the fetus is disabled. We demand that decision makers acknowledge the right of disabled women to choose for themselves. We also refer to the text in the Beijing Platform for Action.

## Education

Poverty and disability among women and girls are closely linked. We demand effective access to education and employment as the primary tools for fighting poverty. We urge that education be used as the primary key for girls and women to be able to lead integrated and participatory lives in their communities.

We demand that decision makers include the education and skills development of girls and women with disabilities as an integral part of the educational system. Language and communication skills development are especially important in those countries where the use of several languages is practiced. Sign language education and development should be promoted. Similarly, blind girls and women should have the opportunity to learn Braille and other skills to enable literacy and communication.



Local culture should be allowed to provide opportunities for girls and women to be recognized as full participants in meaningful social and economic roles.

We urge that both parents and teachers of girl children with disabilities receive further training in order that the quality of overall education be raised. We also urge that teacher training curricula include a disability component.

We demand that education provide effective opportunities for girls and women with disabilities to become empowered. The need has never been higher for organized women's groups to provide effective role models so that girls and women can take up leadership roles, increasing their self reliance.

We urge the development of mentoring programs for girls and young women with disabilities and demand the inclusion of positive images of women and girls with disabilities in the media.

#### Employment

We demand that existing economic inequalities between women and men be equalized, and that the economic contribution to the society by women with disabilities be recognized. Women with disabilities should be afforded full support to pursue their ambitions and skills development regarding the use of their capabilities to support themselves and their families.

We urge that women with disabilities be encouraged to establish micro enterprises, for example, in the development of marketing devices, sales representatives, catalogues, etc, to bring the goods/products of other disabled women to market. Banks should recognize the multiple value of giving loans to women's business enterprises. Governments must recognize the efforts of women engaged in micro enterprise development with tax credits and other appropriate benefits. We demand that world commercial communication groups present in their programming positive examples of women with disabilities in their businesses.

#### Health Care

Because of the discrimination and ignorance of medical professionals and extreme poverty, women with disabilities do not have the same access and opportunities for health care as their able-bodied counterparts. The power of health care professionals, particularly in the mental health and developmental disabilities arenas will not be given up easily. Disabled women are dying prematurely as a result of not getting the care we need. Disabled women do not receive adequate personal assistance, assistive technology and supports because of lack of funds.

Therefore we demand that:

1. Women take power and control over their own health care, including having the choice of what medical tests and treatments they wish to have. Parents of disabled girls receive full information on the outcomes of medical procedures so they can give informed consent.
2. National Health policies and bureaucracies be accountable for improving the access, availability and affordability of high quality, culturally appropriate health care for disabled women and girls.
3. Schools for health professionals offer affirmative action to students with disabilities and include adequate training on the needs of women and girls of disabilities, including community-based rehabilitation and reproductive education.
4. Adaptive equipment, appropriate to local conditions, be



developed Studies be launched to evaluate the outcomes of medical procedures from the point of view of people with disabilities. Multidisciplinary health and medical care and research be done to provide a more holistic picture of gender specific impairments and diseases.

5. Disabled women be trained to be the leaders in research on disabled women's health care needs.

6. In war torn areas quality field-based health services be provided for disabled women and girls.

7. All countries insure that rehabilitation services are available to disabled girls and women without sexual bias.  
Sexuality

Disabled women internalize the mythology of asexuality. Disabled women have internalized the notion that our bodies are not worthy to be loved. Many woman and girls are extremely lonely and touch deprived. We want a disability sexual culture focused on our entitlement to pleasure and love, understanding the advantages of possessing bodies and functions different when compared to women's majority culture.

We urge that:

1. Women have a safe and private place to discuss with each other their sexual lives, desires, hopes and questions.

2. Disabled women and girls receive accurate information about sexuality, including training to publicize the good word that all disabled women are sexual and sexy and can give and receive love making in a variety of ways.

3. Disabled women be educated to work in women's health services, including training as sex educators and leaders in research on disabled women's sexuality.

#### Communication & Technology & Accessibility

We demand an end to the systematic denial of disabled women to appropriate information and mainstream lines of communication.

We demand that there be guidelines:

1) to ensure that disabled children and adults of both sexes are integrated into mass media programming, including advertising;

2) these portrayals must be positive, sensitive and life enhancing. This includes public education campaigns designed to prevent disability, such as immunization.

We demand that all technical methods of communication are designed for universal use by disabled and non-disabled persons.

We urge that the communications and information needs of disabled women who are poor and have not received an education are given a higher priority.

#### UN Conventions

We further believe that the United Nations and our countries should intensify efforts to implement all existing conventions concerning disabled women and girls. Such actions should be effectively overseen by the United Nations bodies responsible for monitoring of these instruments, together with the non-govern-mental (NGOs) organizations concerned. Special





cooperation should be established between the units responsible for disability, gender, human rights and NGO issues. Such actions should be applied at the local, national, regional and international levels.

We urge the United Nations and other relevant bodies to take immediate action regarding:

informing about the existing conventions using easy-to-read language, accessible formats and local languages

initiate the building of new knowledge with respect to women and girls with disabilities using surveys, research and case studies

encourage the development of dialogue with decision-makers at all levels

facilitate the co-sponsorship with NGOs of seminars dedicated to training of women and girls with disabilities about methods to implement policy and to take up decision making positions.

#### Affirmation

We hereby reaffirm the establishment of a global sister network among women and girls with disabilities.

We affirm our membership in WILD- Women's International Linkage on Disability.

Washington, D.C., USA, June 20, 1997

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Women's Institute on Leadership and Disability  
Eugene, Oregon, USA - June 1 - 14, 1997

Loud, Proud and Passionate! was the rallying cry of 32 women with disabilities who participated in Mobility International USA (MIUSA)'s International Leadership Institute for Women with Disabilities, in Eugene, Oregon, from June 1 to 14, 1997. Grassroots organizers, teachers, journalists, writers, physicians, students, and mothers, Leadership Institute delegates came together to exchange experiences and build skills and strategies to counter the double discrimination faced by women with disabilities, which results in illiteracy, unemployment, poor health, isolation, disenfranchisement, and lack of leadership opportunities.

By Mobility International USA

The Institute was held as an intensive training opportunity for selected women prior to their participation in the International Leadership Forum.

Focus on Solutions

Using the model developed by MIUSA over 16 years of international exchange and leadership training, the Leadership Institute curriculum was a non-stop combination of seminars, challenge and team-building exercises, and cultural activities. In seminars on topics such as leadership issues, organizational development and funding, sexuality and reproductive health, addressing violence, deaf culture, income generation and employment, using the media, advocacy through policy and legislation, and using the Internet, delegates explored ideas for facing problems, practiced skills, and exchanged resources. Through outdoor and physical activities such as aerobics, sports, camping, swimming, and dancing, delegates challenged preconceived limitations and experienced the expanded possibilities of women with disabilities working together.

Based on recommendations from grassroots disabled women



leaders from around the world, the Leadership Institute focused on working toward positive, practical solutions. The goals of the Leadership Institute were:

- to provide opportunities for delegates to share resources and strategies to empower women with disabilities throughout the world, and

- to create a system for communication to exchange information, technical support, and mutual encouragement between women with disabilities who are working for positive changes in their communities and countries

#### Diversity: Who Says We Can't Work Together?

"For the first time in my life, I have felt secure in giving my comments. In other conferences, I have never felt that my comments were important." Leadership Institute delegate.

MIUSA welcomed delegates to the opening session by introducing the first of many challenges to the group: how to create cohesion and ensure equal participation among a group of individuals reflecting the diversity of the world in language, culture, and disability. Delegates represented Australia, Bangladesh, Brazil, Canada, France, Guatemala, Indonesia, Palestine/Israel, Kenya, Malawi, Mauritius, Mexico, Nepal, Nicaragua, Philippines, Romania, Russia, South Korea, Thailand, Uganda, USA, Uzbekistan, Vietnam, Zambia, Zimbabwe. They used over 20 spoken languages and four sign languages. Among this new sisterhood were women who are blind, deaf, have low vision, are paraplegic or quadriplegic due to polio, spinal cord injury, arthritis, or muscular dystrophy, have amputations of leg or arm, walk with crutches or canes, or are of short stature.

Our first team-building experience was to make a group commitment to ensure full communication and equal participation by all the women at the Leadership Institute. Everyone pitched in. Creative and flexible systems for communication soon emerged, incorporating shifting seating arrangements and various combinations of interpreters and delegates mixing Spanish, English and Russian verbal translation, lip-reading, and sign language interpreting. The experience was eye-opening for many participants who had little previous experience with cross-disability, cross-cultural collaborations.

#### Innovations

One of the most exciting aspects of the Leadership Institute was learning about the innovative solutions women with disabilities are finding to address problems of women with disabilities in their countries. Working in small groups, each delegate proposed a specific project to benefit women with disabilities, and received feedback and practical suggestions from her group members. It was no surprise that "funding" was among the most commonly mentioned difficulties, and women offered strategies for carrying out projects with little money, or for identifying creative sources for funding.

In a seminar on proposal writing facilitated by Corbett O'Toole of the Disabled Women's Alliance (USA), delegates distilled the goals and needs of each project to concise one-page descriptions to present to potential funders. Some of the projects presented by Leadership Institute delegates included:

- Revolving Loan Programs for women with disabilities in Southern Africa

- training program for women with disabilities to become sign language interpreters and teachers of Braille and mobility and



orientation in San Luis Potosi, Mexico  
 secretarial training program for women with disabilities in  
 Nepal  
 Grinding Mill project to generate employment and income for  
 women with disabilities in Zimbabwe  
 English and computer training for women with disabilities in  
 Vietnam;  
 a Bakery run by women with disabilities in Guatemala;  
 Leadership training courses for women with disabilities in  
 France, Romania, and for minority women with disabilities in  
 Canada;  
 center for women with disabilities in Korea  
 vocational training centers for women with disabilities in  
 East Jerusalem

#### E-Mail Activism: Using the Internet

"For the first time, I have knowledge of how e-mail and computers work. When I go back home, I will go for training. No one will this time tell me that I can't use computers because I have one hand. I know now that I can do it." Leadership Institute Delegate.

Maureen Mason, of the Institute for Global Communication's WomensNet, presented a day-long workshop on using computers and the Internet for international communication and activism. In the morning session Maureen introduced the Internet; basic use of e-mail and the World Wide Web. Mike Thomas, a trainer for the Oregon Commission for the Blind, demonstrated adaptive equipment for people with visual disabilities. Delegates with and without visual impairments were enthusiastic about the potential of this technology for increasing participation of blind women in networks of communication. Initial shock at the price tags of the equipment was countered with a flurry of ideas for sources of donations and fund-raising. In the afternoon, delegates broke into small clusters for intensive training and hands-on practice in using e-mail, browsing the Web, basic Web page design, and desk-top publishing.

The day concluded with a strategy session on how to stay in touch in order to maintain this network of women with disabilities after the Leadership Institute. Delegates were enthusiastic about the relatively cheaper cost of e-mail for communication, since much of their work is currently done by phone and fax. However, many women pointed out problems such as lack of equipment, unavailability of technical support and unreliable telephone lines as potential barriers to using email. The group proposed a system of communication using a combination of e-mail, fax and postal mail, in which each organization or individual takes a role in the passing of information depending on technical and financial capacity.

#### Ropes Challenge Course

" The Challenge Course gave me insight into how much strength comes from trusting others for support - physical, mental, emotional. As a leader, this is really important for me, reminding me of how strong I am when with other women with disabilities." Leadership Institute delegate.

On a rainy afternoon, delegates ventured into the Oregon woods to undertake what many would later describe as the most transformative experience of the Leadership Institute. The Ropes Challenge Course is an intensive workshop in which participants use teamwork and strategy to accomplish a series of physical challenges. In small teams, delegates worked together to move





every woman over a 10 foot wall, to cross a rope bridge suspended from one 20 foot high platform to another, and to reach a target while "flying" blindfolded, suspended in the air. Women pooled their various strengths, props and creativity as they climbed, boosted, hoisted, and directed each other to reach their goals. Tableaus were framed: at "The Wall", arms reaching down to a woman ascending a pyramid of other women, crutches becoming ladders propped on arms of wheelchairs. At the "Flying Angel", a woman suspended in the air, signing directions to her comrades below to shift the counterbalance of her ropes as she stretched to reach her target. On "The Bridge", a woman who walks unevenly with canes on solid ground, hesitates on a platform high in the air, then, responding to the encouragement of her team and her own determination, moves forward on the ropes between trees.

Every woman, with the help and encouragement of her colleagues, went up and over the obstacles which on first assessment seemed insurmountable. As one Leadership Institute delegate described the experience, "The Challenge Course reminded me that challenging things are not always impossible to overcome and teamwork is very important."

The Challenge Course and other physical activities had another kind of powerful impact on the Leadership Institute delegates. Many activities, including swimming, rafting, camping, wheelchair basketball and aerobics, were "first experiences" for these accomplished women, and contradicted the limitations which had been imposed on them, not only by other people but by themselves. One woman described, "I had always wanted to climb trees, go swimming, and do river rafting. So protective of me, my family often discouraged me to do things. After these experiences, I'm more daring and independent. I am more aware of my capabilities as a woman with a disability". Another woman stated: "This experience was an eye-opener to me because I participated in most of the challenging courses which non-disabled people think that we can't do. So when I go home I will participate fully in the challenging activities and I will encourage women with disabilities to change their attitudes toward themselves."

#### Activism for Change: Rights, Laws, and Organizing

"I gained insight into what it means to challenge internalized oppression. Regardless of what is stripped from us, we can always maintain our dignity." Leadership Institute Delegate.

"I was so lonely before I came here. Why? Because there were no people who understood my vision for a movement for the rights of women with disabilities" Leadership Institute delegate

Mary Lou Breslin and Pat Wright of the Disability Rights Education and Defense Fund (DREDF) opened the workshop on Activism for Change with a discussion of the power of action rooted in a "Rights-bearing Attitude". They spoke of the importance for women with disabilities to find common ground in shared experience, to overcome differences and work together, using every woman's strengths, and to be persistent in the face of barriers.

As consulting session was held where delegates served as advisors for three of their members, Venus Ilagan (Philippines), Susan Chitimbe (Malawi) and Kim Mi Yeon (South Korea). Each "client" presented a brief outline of the goals and activities of her organization, and asked for help from the "advisors" in dealing with a problem or difficult situation. The room rang with the collective wisdom of 40 women of different countries.

Women shared strategies for stretching grant funds by creating self-sustaining projects, which teach skills to women with disabilities while generating income through products or services. "Consultants" encouraged their sisters to persevere in





efforts to develop organizations run by women with disabilities, and offered political strategies for creating successful women's organizations while maintaining necessary relationships with male colleagues and politicians.

Responses were especially charged to the universal problem of securing loans for business ventures by women with disabilities. Around the world, women with disabilities continue to be considered bad credit risks, or not seriously considered at all, in spite of steps such as certified loan management and business training programs, and collateral funds for women with disabilities. MIUSA ventured a proposal: women with disabilities need our own bank. Can we create an International Women with Disabilities Loan Fund, managed by and for women with disabilities?" The response was resounding: let's do it!

#### Organizational Development and Funding

"I am encouraged. I will take more opportunities for fundraising. I will begin my new life as an activist of women with disabilities movement" Leadership Institute Delegate.

Creating and sustaining organizations, fundraising, and micro-credit were high on the agenda of a two-day seminar on organizational development and funding. Laurie Laird, of the Global Fund for Women, advised women on the process of applying for funding, starting with learning about the funding organization - what kind of projects they fund, their guidelines-before approaching them. She advised that developing a relationship with the funder is crucial, and recommended that organizations begin by submitting a modest proposal, and by involving a more well-known organization as a "counterpart" if the applicant is a new organization. Kicki Nordstrom, Coordinator of the Women's Committee of the World Blind Union, offered insights and a publication on starting organizations of women with disabilities, and suggested a number of resources for funding. A workshop with Jenny Kern and Jan Sing of Whirlwind Wheelchair Women of the Wheeled Mobility Center began with a demonstration of basic wheelchair building techniques, and evolved into a discussion of the business of wheelchair manufacturing, how to train women with disabilities to be technicians and business women, and how to make a business successful.

Geoff Davis of the Grameen Foundation described the concept of village loan programs, in which small groups of women are granted small loans to start businesses, and share the responsibility of repayment. Delegates shared their experiences with micro-credit programs, asked many questions about starting loan programs in their communities, and continued to explore possibilities of creating an international revolving loan fund, based on the village loan concept, run by and for women with disabilities. Geoff described some of the key ingredients of successful programs, including business and technical training for the loan participants. Leadership Institute delegates organized a working committee to follow up on the loan fund idea.

#### Moving Forward

"After the MIUSA Leadership Institute, I'll never be the same again. I'm more daring and independent. I'll share these new experiences with other women with disabilities. My organization will see a new woman, a daring and passionate woman". Leadership Institute delegate



As they prepared to leave Oregon, women with disabilities from around the world shared the new goals that they carried home, and the steps that they planned to take to move toward them. Some women described ideas for conferences on leadership training, violence against women with disabilities, women's and disability rights, or health issues. Others described plans to create organizations, support groups and newsletters, by and for women with disabilities, including cross-disability groups and groups of Deaf women. Several women were excited about incorporating experiential or physical activities into programs for women with disabilities. Media campaigns were planned by delegates from several countries.

MIUSA agreed to work with women with disabilities on the creation of a revolving loan fund, and to help initiate a fax, post and e-mail correspondence system. MIUSA also sent five donated, retrofitted computers and monitors home with Leadership Institute participants who had no access to computers, to ensure that women have the means to maintain communication and mutual support. (Another 10 computers will be ready and sent to delegates in the next few months.)

As the Leadership Institute drew to a close, Leadership Institute delegates and MIUSA staff prepared to fly to Bethesda, MD, to participate in the International Leadership Forum for Women with Disabilities. Most Leadership Institute delegates took high profile roles at the Forum, as workshop convenors and presenters, including Venus Ilagan, who served as Keynote Speaker representing the Asia Pacific region.

#### Lasting Effects

In the last days of the Leadership Institute, delegates took stock of their accomplishments. Some were tangible, including the compilation of autobiographical essays and photographic portraits of Leadership Institute participants (to be edited into a book), two issues of a newsletter written by teams of delegates, and a videotape, with women with disabilities on each side of the camera, documenting personal accomplishments and offering motivation and support to other women and girls.

Based on responses from the delegates, the Leadership Institute accomplished its goals: to empower women with disabilities by providing opportunities for exchange of strategies, information and resources, and training in practical skills. Reflecting on their experiences in the Leadership Institute, women with disabilities described themselves as feeling more confident, less isolated, and more equipped with skills, information, resources and ideas to do their important work at home. As one Leadership Institute participant summed it up:

"The best time of my life was during this two weeks of training. I understand and felt really understood in a group of women with similar experiences to mine. Even though our cultures and languages are so different, I learned that our challenges, objectives, and dreams are the same, and I will not feel alone ever again."

#### Thanks

MIUSA wishes to thank the many contributors who made the Leadership Institute for Women with Disabilities possible: the WK Kellogg Foundation, The Dole Foundation, the US Information Agency, the Open Society Institute, National Institute on Disability and Rehabilitation Research of the US Department of Education, the Western Regional Resource Center, Travel Team,



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Remarks by the U.S. Secretary of State

All women, whether we have disabilities or whether we do not, are ready to claim our rightful place as full citizens and full participants in every society on Earth.

Ours is a unifying vision, based on the truth that in our era, security, prosperity and freedom are not finite, nor are they the rightful property only of some people in some places.

If we plant the seeds and till the soil, those precious commodities will grow. And more and more people in more and more countries will become beneficiaries and contributors to our global community.

To that end, I am very encouraged by the work the organizations sponsoring and participating in this conference have done and are doing to advocate, educate and lead. You are doing an outstanding and important job. But as I am sure you agree, there is a very long, long way to go. Marginalization

There are more than three hundred million women with disabilities in the world. In many societies, they are consigned to the margins-not admitted to schools, rejected by employers, denied access to health care. We cannot afford this loss. We need your strength and skills. If we are to build the kind of future we want, women with disabilities cannot be marginalized, women and girls with disabilities must be empowered.

This morning at this historic conference, I assure you that I will do everything I can to see that America does its part in advancing our common agenda. First, closest to home, I want to see a State Department and foreign service that is truly open to the talents of all.

Spurred on by Deidre Davis, the Deputy Assistant Secretary of State of our office on Civil Rights, we have eliminated barriers to full participation. I have been told that a record number of individuals with disabilities took our foreign service exam last November, and that 146 passed.

I look forward to many of them joining the foreign service, and I encourage any of you who are eligible and looking for an interesting change in career to consider taking the exam, as well.

Second, as a matter of policy, the United States can and will be telling the story worldwide about what we have been able to do here through our knowledge of rehabilitation, the strength of our civic organizations, the liberating nature of our technology and the justice of laws such as Americans with Disabilities Act. After all, if we Americans can export our strategies for selling hamburgers - surely we can export our strategies for meeting the needs and benefiting from the skills and strengths of persons with disabilities.

Third, the connections between poverty and disability, between maternal health care and preventing disability, and between community-based rehabilitation and independence for disabled persons are not widely understood. But there are many who do understand at USAID, in the Peace Corps, in UN organizations and programs and in the PVOs that support economic and social development worldwide. Their challenge is finding the resources they need to keep us all moving forward.

As Secretary of State - I hate to tell you this - I don't have a blank checkbook, but I do have a bully pulpit. I will do my absolute best to make the case on Capitol Hill and





around America that by helping these organizations, we give a hand to friends everywhere, we honor our values and help secure our own future.

## Landmines

Fourth, we have the problem of landmines. We must do more to cleanse the Earth of their pernicious presence.

We must do more to rehabilitate and provide for full entry into society of the victims. And we must negotiate an agreement that will end forever the danger landmines present to women and children around the globe.

As long as I live, I will never forget my trip to Angola. I don't think I've ever seen so many injured people as I have in Angola. And when I went there, out into the villages, to see children tethered to their houses so that they would not escape into the fields to get blown up by landmines. Landmines are a scourge, and we call on all of you to help us in this very, very important issue.

## Violence

Fifth, here in the United States, our top priority in implementing Beijing has been to halt violence against women. That is also a goal of American foreign policy; because the truth is that today, around the world, appalling abuses are being committed against women and women with disabilities. These abuses range from domestic violence to dowry murders to mutilation to forcing young girls into prostitution. Some say all this is cultural and there's nothing that can be done about it. I say it's criminal and we each have a responsibility to stop it.

Finally, I will say to you now what I said to you in Huairou. It is past time - way past time - for the United States to ratify the Convention on the Elimination of all Forms of Discrimination Against Women.

Here in the United States, the Americans with Disabilities Act has made us a leader in promoting full participation by persons with disabilities. But a year ago, when the National Council on Disability issued a report asking whether our foreign policy had a coherent approach to disability, the answer was no. This is not an acceptable answer and, fortunately, it is not an answer that will remain accurate for very long.

## New U.S. Policy

Within a matter of weeks, USAID will be issuing a new policy and action plan on disability and development. That document will express the agency's commitment to reach out and include persons with disabilities in its programs and place this issue prominently on our development agenda with governments that receive our aid.

The new policy is based on a recognition that people with disabilities have the same need for food, health care, shelter, education and training as others, but are often denied access to programs that meet these needs. The solution is greater foresight, wider consultation and better planning. There is no reason on Earth, for example, why a child with disabilities should not be able to sit in the same classroom, learn the same skills and dream the same dreams as her or his fellow students.

There is no reason on Earth why an adult with disabilities should not receive the same help in starting a small business or learning a trade.

There can be no excuse for failing to take access into account when constructing shelter or designing a community center



or developing a source of potable water. The lesson we should all have learned by now is that the best way to prevent barriers to access is not to erect them in the first place.

In this connection, let me say it to you before you say it me. Far too many U.S. embassies remain insufficiently accessible to persons with disabilities.

I have asked our Office of Civil Rights and our Office of Foreign Buildings to produce a plan to correct that wherever we can as soon as we can. And I can promise that when the U.S. Government builds a building overseas, that building had better be accessible to all, or they will owe an explanation to me as Secretary of State.

Since Beijing, we have moved forward and we will continue to move forward as long as conferences such as this and people such as you continue to reach out to each other and to challenge societies and governments to do the right thing. That is your job. It is the job of governments to create a basis in law and in the community to remove obstacles to the full participation of women and of persons with disabilities in the economic and social life of their nations.

At this conference's center, and at the heart of the disability agenda, is the simple premise that every individual counts. That is the philosophy of America at its best. And that has been the motivating force

for the movement to advance the status of women and women with disabilities for longer than any of us have been alive.

This philosophy is not based on any illusions.

Advocates of social progress have seen far too much of hardship and heartbreak to indulge in sentimentalism. But we live in a nation and a world that has been enriched beyond measure by the survivors, by those who have overcome obstacles to build platforms of knowledge, understanding and accomplishment from which others might advance.

It has been said that all work that it is worth anything is done in faith. While respecting our diversity and building our unity, let us all keep the faith that our persistence and dedication will make a difference; that every friend transformed by our caring, every life enriched by our giving, every soul inspired by our passion and every barrier to justice brought down by our determination will ennoble our own lives, inspire others and explode outward the boundaries of what is achievable on this Earth.

Towards that end, for all you have done, I salute you. For all that you will do, I admire you. And for your attention and kindness this morning, I thank you very, very much.

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International Development Assistance & Disabled Women

Birgitta Andersson is the Chairperson of the Swedish Organizations of Disabled International Aid Association (SHIA)

I have had the pleasure to chair the board of SHIA for six years. SHIA stands for Solidarity, Humanity, International Aid, with the subtitle - Swedish Organizations of Disabled International Aid Association. SHIA is an association established to coordinate development cooperation between Swedish organizations of the disabled and sister organizations in developing countries. I am also the president of DHR, The Swedish Federation of the Physically Disabled.

Disabled Women's Network

To be able to stimulate and strengthen the participation of

Department of the Interior, Bureau of Land Management  
Washington, D.C. 20250

Dear Sir:  
I have the pleasure to inform you that the Bureau of Land Management has received your letter of the 10th instant regarding the proposed acquisition of the 100-acre tract located in the County of ... State of ... The Bureau is currently reviewing the information provided and will advise you of the results of its review as soon as possible.

Sincerely,  
[Signature]  
Special Agent in Charge

women in the Swedish organizations of the disabled we, women with disabilities, have initiated a network. Today I am proud to tell you that nearly 50 percent of the leaders of the national organizations of the disabled are women.

## SHIA

SHIA, was founded in 1981 by 14 different organizations of disabled in Sweden representing all major disability groups.

At the start SHIA was a small organization with limited activities. Today, all together, SHIA is conducting more than 60 projects in 18 countries in Asia, Africa and Latin America

The main objective for SHIA is to support organizations of persons with disabilities in developing countries and to participate in development programs/projects aimed at improving the situation for persons with disabilities in these countries.

To achieve this SHIA uses different strategies but the core of the activities is our operative development support. We divide our development programs and projects into three main categories; organization support, rehabilitation and education.

An other important role played by SHIA is awareness raising. The objective is to influence different organizations and institutions in the development field to identify persons with disabilities in their work, and to increase the quality of the support, mainly by making sure that persons with disabilities and their organizations have a major input in the activities concerned.

During more than 15 years experience of supporting people with disabilities and their organizations we had realized that mostly men benefited from our support. Men were leading the organizations and therefore decided what should be on the agenda. It is obvious that men's priorities often are different from women's.

Through my engagement in SHIA I have been involved in many fascinating meetings. Let me tell you about a group of visually impaired and physically disabled women that I met in Ghana. We sat together discussing common experiences concerning the conditions of being a woman with a disability. We talked about the everyday struggle - about how to support oneself, to raise a family, and how to cope with the prejudice in our surroundings. They were colorful, beautiful and talented women. I was very impressed by them. Then I asked them what they considered most difficult in being a disabled woman. They answered quickly - to be considered not good enough as a woman, wife and a mother.

## Lack of Influence

In many organizations women were lacking influence. Even if some organizations had formed separate women wings, the male leaders made sure to keep their influence by placing family members such as wives or sisters on leading posts of the wing.

To be able to put forward a strategy that could make sure that also women would benefit from the support given by SHIA, a special women committee was appointed. The committee started to work by conducting a survey among women in the organizations cooperating with SHIA. The survey was compiled in a report "The situation for women with disabilities in countries cooperating with SHIA " in 1994.

In this report the women clearly express their situation and point out areas of special concerns. These areas are:

- ? The right to an income,
- ? The right to education,
- ? The right to family life,
- ?? The right to participate in organizations of the disabled.





The report radically increased the awareness among SHIA's member organizations and made them take concrete action. Today about one third of SHIA's 60 projects contain support directed to women with disabilities.

### Women's Priorities

For most women the first priority would be to be able to support themselves and their families. Many projects directed to women therefore contain measures to address this aim.

Different kinds of micro credits have shown to be a successful way to create income possibilities. It has also been proved that if women are playing a key role in conducting and implementing micro credits, it is a guarantee for success.

The second priority of most women is to get access to education. This can include basic education, higher education or vocational training.

We know that a vast majority of women with disabilities in developing countries are refused basic education. It is a challenge to provide education, especially aiming at adult women with disabilities.

Through our experiences we have found that education as a component in community based programs can be very successful. The community based approach is a possibility to provide education or vocational training close to the women. This enables these women to combine education and training with household duties and family life.

Then the fight for education becomes easier. In many cultures, it is seen as impossible for a woman to leave home and travel on her own to work or study. If she has a family of her own it is even harder.

Another example where we try to provide education on women's condition is in Argentina. SRF, The Swedish organization of visually impaired, is supporting a "mobile school" that can provide basic education to visually impaired women. By making the school mobile more women will be able to attend and benefit from the project.

The third priority I think differs between individuals but for many women it is important to increase their influence and their possibility to act and speak for themselves.

### Early Discrimination

It is important to remember that discrimination and exclusion of women with disabilities start in early childhood. Mrs Gertrude Fefoame involved in the SHIA project in Ghana has described the situation as follows:

- A girl and a boy child are valued from different criteria. A boy is valued from his production capacity while a girl is valued from her capacity to reproduce. When a child is born with a disability this hits hard on both boys and girls. Even though it is hard it is often possible to convince parents that the boy with some practical help and training will be able to produce, to earn a living, even though he has a disability. But to make the parents envision their disabled girls as a capable mother and a wife is very difficult. This fact limits the value of a disabled girl child dramatically and we know that many disabled girls will not survive.

The World Bank has said:

- To support a woman is to invest in a whole family, to support a man is to invest in one person.

I believe these lines contain an important truth. To achieve a sustainable change for women with disabilities we have to start working and supporting the children.

As I said we have realized that supporting the organizations



of disabled does not automatically benefit women. This also goes for children with disabilities.

Disabled children are often not offered membership in the organizations of the disabled and therefore have very limited possibilities to speak for their rights and needs. By our efforts to strengthen women with disabilities we believe we will also strengthen the role of children in the organizations.

#### Support for Village Women

From the experience of SHIA we have examples showing that support channeled through women is often used and spread efficiently. One of the local branches of my own organization, DHR, is giving a small support to a group of 200 women in four villages in a rural area of Tanzania. Out of a very limited economical input the women have managed to give both some practical support to women with disabilities and to start up revolving loan funds that will give the women a possibility to earn an income to support their families. The project has also mobilized the women who are now much more active in their communities. Activities like the project in Tanzania can act as important kick off for other measures in order to strengthen women with disabilities. SHIA is actively supporting exchange of experiences among our partners in developing countries. As they are working under similar conditions they can give an important contribution to each others work.

SHIA is trying to empower women from our cooperating partners by giving them the chance to speak for themselves. An example of this is the SHIA delegation of disabled women at the NGO Forum arranged in connection to the UN Women Conference in Beijing, in 1995.

#### Breakthrough

By quoting a few lines from our Beijing report I think I will give you a picture of what the presence of the SHIA delegation meant;

"It was at the NGO Forum in Huairou and at the UN conference in Beijing, that we - women with disabilities - broke through and became visible. I do not think anyone returned from either the Forum or the conference without noticing our presence and the fact that we had been speaking for ourselves. We became a group to count on within the women movement. A group with the capacity to act, to participate and stand up for our rights." (Women walk on water).

Many girls and women with disabilities go through life without any confidence. Nobody asks for their experience, their ideas or has any expectation concerning their capacity.

Ms. Hema S. Nugghalli from India, who is also present here at this conference, was one of the participants in the SHIA delegation at the NGO Forum in Beijing. In this role she was asked to prepare a speech concerning the situation of disabled women in India. When she told us how she went about to prepare this paper I thought it was a comprehensive example of empowering of women with disabilities on the grassroot level:

To make sure she would give a true picture of the situation of disabled women Ms Nugghalli felt that she needed to consult disabled women living in the countryside or in the slum areas. Women who had not been active in any NGO. By word of neighbors and family members Mrs Nugghalli managed to identify a number of disabled women. She invited them to a meeting to share their experiences. Most of the women did not accept to come. They did not feel that they had anything to contribute with. It took a lot of persuasion, but in the end Ms Nugghalli managed to gather around ten women. After a hesitating start the women began to realize that they had a lot in common and that it was



strengthening to share experiences. Apart from serving as the basis for an excellent presentation in Beijing this meeting also became an important starting point for the women involved. They decided to continue to meet and to start saving money to facilitate this.

### Standard Rules

A last comment I would like to make concerning our strategy to support women with disabilities, is concerning the UN Standard Rules:

Mrs. Chicu Mwalutambi, Tanzania, another of the delegates at the NGO Forum, talked very clearly about the importance of the Standard Rules. Her opinion is that the Standard rules radically have strengthened the status of disabled people in a global perspective. She says;

- The fact that the UN has discussed and decided on a document stating the rights of people with disabilities is a great step forward.

It is a future challenge for SHIA that together with our cooperating partners, to penetrate the Standard Rules from a gender perspective and to formulate a method to put them into practical use. Within this process it is important to also include essential statements from other relevant documents such as; the official report from the Beijing conference and the report from the Social Summit in Copenhagen. Other documents that must be used are the Convention on the Rights of the Child and the Convention of Human Rights.

### Women's Wings

Most of the organizations co-operating with SHIA have separate women sections. Still this is not a guarantee for the influence of women. To achieve a sustainable result, the women issues have to be turned into "gender issues". By this I mean that there must be a consensus within the organizations that the women have as much as men to contribute and therefore need to be actively involved in all decision making.

An interesting example of a woman's wing fully involved is in ENAB, Ethiopian National Association of the Blind. The women in ENAB have managed to organize a whole range of activities and to fund raise for them. One example is the wing arranged a show at the stadium of Addis Abbaba. In addition to bringing in an important economic contribution this also gave ENAB a lot of important coverage in Ethiopian media.

In other organizations the women wing is more a product on a paper and the women struggle hard without receiving any attention from the male leaders. In some cases the women even discuss that the only way to achieve influence is to form a separate women's group.

So far SHIA has very limited experiences of this kind of projects but it is an interesting discussion to follow.

### Capacity Building

For the last two years SHIA has supported the capacity building within the women's structure of the international disability movement. The World Blind Union has carried out seminars in all their regions. The seminars led to the formation of regional women structures whose task are to support and mobilize grass root work among women with disabilities. SHIA has also supported seminars arranged by the World Federation of the Deaf and the international organization of deaf-blind people.

Role Models





There is a great need for role models in the work to strengthen women with disabilities. Therefore it is important to give women with disabilities the opportunity to develop their leadership skills. Women are needed as spokespersons both on central level and on local level. This is a basic condition to be able to mobilize women with disabilities.

#### In Conclusion

At last I would like to say that SHIA, and its member organizations, have gained a lot from our work to support women with disabilities.

Personally I also feel that meeting other women with disabilities is an important contribution in my life. I have experienced many both personal and more general findings through sharing ideas and views with other women. This concerns the relation and communication between men and women but also our situation in society and the sometime hidden negative attitude we face in our daily life. Through the dialogue with other women I have also received much practical advice that has made my life easier.

To enable a conference like this where we women with disabilities from all over the world have the possibility to meet is a great opportunity both for me personally and from the perspective of SHIA's member organizations. Therefore I would like to thank you once more for the invitation.

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#### Partnership: The Key to Growth

Francine Arsenault is the Chairperson of the International Center for the Advancement of Community Based Rehabilitation and Past-Chairperson, Council of Canadians with Disabilities.

As a woman with a disability I want to share with you some of the important things I have learned from my own life and from working with both the consumer movement of people with disabilities and the community based rehabilitation movement. My purpose is to bring to your attention the value and critical need for partnerships throughout the process of ensuring community participation for women with disabilities. To do this I will present some of the partnerships that have been critical in my own life and I'll extrapolate to highlight the pertinent principles of partnership.

#### Family: The First Partnership

The old saying goes that you can pick your friends but you are stuck with your family. Well, family is probably the most crucial partnership you will ever form and in my case I couldn't have picked better. My parents were very young but broad-minded and resourceful. When I contracted polio at eight months of age, they took the doctor's advice and put me in isolation for a month to protect my mother who was five months pregnant, my brother and the community whom they thought I threatened. When I was released to them, they immediately started to adapt their lives and my activities to make me an integral part of their world. They had virtually no training as to how to deal with me but they took each day as it came. They learned as they went along, they made adjustments and together we found ways of keeping me connected to my community.

THESE ARE THE RESULTS OF THE INVESTIGATION  
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Critical to ensuring the potential of children with disabilities is the development of supports for parents. Community based rehab has focused to a large extent on providing information and support to parents of children with disabilities as a means of ensuring, not only the good health of children with disabilities, but to fight against attitudes that can isolate and devalue people with disabilities. To speak bluntly I am dismayed that the consumer movement of persons with disabilities has done so little in the area of supports to children with disabilities and their families. I offer to all of you a challenge to find innovative and empowering ways of assisting families with children with disabilities. The family is truly the most important partnership unit we will ever encounter. If this partnership is unhealthy the damage done can take a lifetime to resolve.

#### Partnership Means Removing Barriers

I grew up in a middle class Canadian neighborhood which included a Catholic school system. Few schools have been as open as mine was in sharing responsibility for me. My teachers worked hard to ensure that I could take part, as much as I was able, in all the activities of the other children. Between 8 and 18, I had 30 operations. This meant full co-operation was essential between my family, the medical professionals, hospitals, school staff, friends and other relatives, to help me achieve what others my age were able to do. For me to complete primary school, high school and college, those surrounding me had to be flexible, see my true potential and be prepared to remove barriers.

#### The True Test of Positive Partnerships: Marriage

In 1962, when I was 20, a French Canadian named Ric came riding into my life in an Austin Healey Sprite sports car. This partnership was an unexpected gift. He saw my scarred, limping body and I saw myself reflected in his eyes in a different way than I'd ever envisioned myself before. He took a chance I would fulfill his needs and I risked taking on a role most people felt I might not be able to successfully complete.

Eleven months after our marriage, against the better advice of my doctors, I delivered an eight pound, eleven ounce baby boy to my ecstatic husband. Fourteen months later, our Kathleen was born. Our family seemed as large as we'd hoped but five years later the finishing touch, a golden second son was born. The rheumatic heart condition I'd developed after one of my polio operations became a pressing reason to end this fertility cycle. This phase of partnership succeeded by sharing expectations; each partner doing what they did best and taking responsibility for the results.

#### Responsibility for Creating the Partnership: Parenting

The partnership with my children gave great joy, anxiety, grief and satisfaction. Having three teenagers in one house at one time is hectic, fretful, awe-inspiring but never boring. They had been taught early to be independent because Mother refused her first instinct to be Super Mom. Her son's black eye at six for stopping a school chum from calling Mom a cripple, resulted in a realistic vision that Mother did have limitations, but she could do many things other mothers could not. This partnership now with a 32 year old son, 31 year old daughter and 26 year old son continues on a good footing because we listen and hear each other and remember the needs and expertise of each player. As a parent I learned the critical and necessary skill of beginning partnership. As a parent I was the one who had to take the initiative, I could not just sit back and wait for things to happen. Partnerships only exist because someone recognized first



that they could not do it alone and second they recognized that someone had to get the ball rolling and it might as well be me.

### Partnership with Community Organizations

As my family left the nest, I got involved in organizing "the Village Crafters", a group of 40 highly skilled women who met regularly to maintain the creative history of the village and develop the latent talents of those interested in my rural area. They remain together (twenty years later) because of a like-mindedness, for social interaction and respect for each others' abilities.

After the Year of the Disabled in 1981, I was asked to join a newly formed advocacy organization for persons with disabilities. In the next ten years I had chaired local, regional, provincial, national and international boards of directors. The rules of partnership I had learned in the past served me well here. We learned to empathize with all disabilities and our organizations did not do things for disabled people but taught them to do those things for themselves.

Part of the work I did nationally with the Council of Canadians with Disabilities involved being on a Board of Directors at the International Center for the Advancement of Community Based Rehabilitation (ICACBR) at Queen's University. This partnership is a multidisciplinary partnership in that its projects involve people with disabilities, health professionals, researchers, governments, non-governmental organizations and the communities.

Community Based Rehabilitation (CBR) in India, Indonesia, Bangladesh and throughout the world looks at the prevention of disabilities, the early detection of disabilities and medical intervention into the lives of persons with disabilities. Our program expands to look at the socioeconomic integration of persons with disabilities.

Our aim is to encourage the women who participate, whether they are parents of disabled children or disabled themselves to be involved from the planning of the projects, through the implementation, research and evaluation at the completion of the projects. It has caused enormous attitudinal change for families and the whole community. An example of this process is my friend Pikat. She has enlightened parents in Indonesia who assisted her (she has polio in one leg and uses a crutch) to get a university degree. She applied to be a coordinator of a CBR project that called for her to ride a motorcycle into hill villages and live there for a month to research the situation of persons with disabilities. Local mechanics put a third wheel to better balance her motorcycle and even though she fell off several times, she's inspired the village elders and families who have brought their disabled persons to be assessed. She now regularly visits 18 villages where she assists the communities to remove barriers to the participation. Being a good role model guides people to achieve their full potential.

### Partnership Principles

I believe it is important for us to connect on a personal level but also to try and demonstrate the tremendous impact positive partnerships can have on our understanding of ourselves and on our ability to grow and prosper in the communities in which we live. However, for partnerships to be positive they must be governed by the following principles:

- Partnerships must be open, willing to make adjustments and be based on trust. They must truly be a coming together to make things work and remove the barriers that prohibit participation and growth.



- Positive partnership must focus on abilities. Yes, recognize the disability but focus on the ability.
- For partnerships to grow we must be willing to take chances, not fear taking risks.
- Partnerships must be truly equal, expectations must be shared as well as the responsibility for making things happen.
- Listening is the key to a healthy partnership.
- Respect for each other's abilities is critical.
- Partnerships change, to remain static means to remain in the same place. Be prepared for partnership separation or cancellation. Be open to the formation of new partnerships.
- Partnerships take many forms and may include multidisciplinary approaches including people with disabilities, non-governmental organizations, health professionals, governments, families and the community.
- Partners must be included in planning, research, implementation and evaluation of projects.
- Good role models help partners to achieve their goals.

Our world is far from perfect for persons with disabilities, if it was none of us would be here. There is much work yet to be done. The most productive technique for creating positive change is not new. Critical to our success is the development of creative, inspiring partnerships. I encourage you all in your personal life as well as your work with community organizations to develop creative, growing partnerships that will enrich you and those you work with.

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#### National Council on Disability

Marca Bristo is the Chairperson of the U.S. National Council on Disability (NCD), a federal agency.

When the National Council on Disability was developing and drafting the original Americans with Disabilities Act (ADA) legislation in 1986 and 1987, we were acting on our conviction that discrimination was the single greatest obstacle to full participation by people with disabilities: not severity of disability, not type of disability, not functional limitations imposed by disability, but discrimination. We knew that the programs and benefits which were available could only do so much. Rehabilitation, special education, and other support programs could only take us to the doorstep: a civil rights mandate was needed to open the doors. An accessible and inclusive society must be there, otherwise people with disabilities find themselves, as the saying goes, "all dressed up with no where to go."

#### International Issues

NCD has expanded the scope of its activities to include international human rights issues as they relate to persons with disabilities. For example, we drafted the first-ever United States-initiated resolution on disability policy before the United Nations and worked with the U.S. delegation to the UN Commission for Social Development to negotiate this resolution before 105 countries and to secure its passage through the UN General Assembly in December 1993. The resolution, entitled Positive and Full Inclusion of Persons with Disabilities in All Aspects of Society and the Leadership of the United Nations Therein synthesizes the application of previous, more general, UN documents regarding human rights to persons with disabilities. In

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addition, NCD worked to successfully amend and then pass the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities in order to reflect more progressive approaches to disability policies and programs.

### Promoting Civil Rights

NCD's long history in promoting civil rights for people with disabilities around the world continued in March of 1995, when I participated as a U.S. delegate in the UN World Summit for Social Development. In fact, I was the first person with a disability to be a U.S. delegate at any summit. Since that time, the U.S. Department of State has designated NCD as the official point of contact within the U.S. government for disability issues.

### Policy Guidelines

NCD believes that as the leading democracy in the world, the United States is in a unique position to advance progress toward democracy, equality of opportunity, and the full and valued social participation of people with disabilities on an international basis. Toward this end, the 1996 NCD Summit gathered disability rights leaders with international expertise to "take stock" of current U.S. policy and statutory provisions regarding people with disabilities in other countries in order to develop a more cohesive set of guidelines regarding the treatment of people with disabilities within the foreign policy arena. The U.S. Agency for International Development (USAID) is now developing a policy guidance entitled USAID Disability Policy and a second document, USAID Disability Plan of Action, which will guide implementation of the policy. This action is in part a response to recommendations in our 1996 report Foreign Policy and Disability. NCD also worked collaboratively with the U.S. Permanent Mission to the Organization of American States, other federal agencies, and non-governmental agencies to draft the Inter-American Convention for the Elimination of All Forms of Discrimination for Reasons of Disability, which was recently adopted. Thus, NCD is beginning to catalogue current provisions, analyze areas of congruence/disagreement, and develop recommendations for improved foreign policy and programmatic efforts in meeting the needs of people with disabilities on an international basis.

### Awakening to Action

The road to equality of opportunity is a long one. But we must begin. We cannot afford not to. In his book, *No Pity*, Joe Shapiro describes how Justin Dart, Jr., one of the founders of the disability rights movement in our country, was awakened to action in the area of disability rights during a visit to South Vietnam in the late 1960's. It was in Vietnam that Justin first realized that not only were people with disabilities treated poorly, they were considered subhuman. Here, he was brought to an institution for young children with polio, the same condition that had caused his disability. Inside this metal shed 100 children had been left to die and to be buried in an unmarked field outside.

Realizations like this have changed Justin and thousands of disability rights leaders forever. As the international movement of people with disabilities has taken hold, similar experiences have strengthened the ties between people with disabilities worldwide. Prejudice against people with disabilities and violations of their human rights know no national boundaries.



## Threat of Backlash

How we in the disability community experience life today is quite different from the way we and our peers did only 15 short years ago. And most important, the attitudes toward our achievements have changed as well.

On the one hand, we see new hope and a new understanding of what our potentials and possibilities are. However, on the other hand, as with other political and social movements, just when we seem to be at the brink of achieving our goals, there is a backlash that comes along to stop us.

The post-euphoria period of ADA has been a deep problem for us here in America. We have not adequately prepared for the resistance we should have expected or the myths about ADA that have persisted.

Leaders from other movements have taught us the lessons of backlash. Susan Faludi, a feminist author, refers to its subtle disguises. If we do not recognize them, they will divide and conquer us, breaking us up, pitting us against each other, isolating one disability group only to attack the next. We see that happening today.

Old myths are remarketed as if they were new truths, and we return again and again to face the very attitudes we have been working so hard to dispel. Backlash is at its worst when it goes within, challenging the sense of self that we, as individuals and as a group, have worked so hard to achieve. When we turn the backlash against ourselves and begin to accept those discriminatory patterns, when we begin to believe that maybe we're asking just a little too much, we have to take a good, hard look at ourselves and each other.

Your presence here today strengthens our vision of a new world order that brings people with disabilities into the whole circle of life. It is also a testimony to your belief that we ourselves can be a significant force for change. It is in feminist author Gloria Steinem's words, "a revolution from within."

## Our Challenge

That is our challenge today: to begin to paint a picture of where we want to be and to insist that, no matter what the odds, we will not give up. Eleven years ago, who would have thought that the Berlin Wall would fall, that Nelson Mandela would be released from prison, or that the Soviet Union would break apart? Only those involved in these visions and struggles would have believed that such outcomes could be possible. Nor can we rest on our laurels. Our journey is not over. It will not be easy. An early African-American civil rights figure, Frederick Douglass, put it clearly. "Power concedes nothing without demand. It never has and it never will."

Last week I celebrated my 20th year as a person with a disability. Some people think it's odd when I use the word "celebrated" with regard to my onset of my disability. But I did. You, the movement, have taught me to love myself, my disability, and to be quite proud of it. With this pride we have accomplished great feats. Our challenge today is to teach the rest of the world to embrace us to celebrate us, as we celebrate ourselves. Only then will we be able to build a true community.

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## Introduction

It was about 1960 that I began to work with the National Center for Independent Living. At that time, the center was a small, struggling organization, and I was one of the few people who believed in its mission. I was a young woman, and I was looking for a way to make a difference in the world. I found it in the National Center for Independent Living. The center was a place where people with disabilities could find the support and resources they needed to live independently. I was part of a team that was working to develop a program for people with disabilities who were living in institutions. We were trying to help them move into the community and live on their own. It was a big challenge, but we were determined to do it.

It was a very difficult time. We were working in a field that was not well understood, and we were facing a lot of opposition. But we were also working with a group of people who were very dedicated and who were willing to do whatever it took to make a difference. We were working with people who were living in institutions, and we were trying to help them move into the community. It was a big challenge, but we were determined to do it. We were working with a group of people who were very dedicated and who were willing to do whatever it took to make a difference. We were working with people who were living in institutions, and we were trying to help them move into the community. It was a big challenge, but we were determined to do it.

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From Breakout to Breakthrough

## The Center

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From Breakout to Breakthrough:  
25 Years of Legislative Advocacy

Jane Campbell is the Director of the National Center for Independent Living in England



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## Introduction

I have been in the business of 'advocacy' and 'change' for 17 years. My journey started as an isolated disabled woman desperately attempting to effect change from within a mainstream charity. Now I advocate from a position of strength within the UK Disability Movement. The journey has been long and hard. On an individual level, it has required a test of physical strength and mental flexibility. More importantly, on a collective level, it has required unending commitment to developing and strengthening communication and democracy.

If 'Disability Politics' has taught me anything, it is that 90% of my own personal liberation and the work that followed came directly from learning from other disabled activists and thinkers who have gone before. By understanding their ideas, I have been able to develop projects in disability equality training and infrastructures for independent living. This process has driven my entire working life.

Today I want to describe a particular personal and collective experience that for me sums up Advocacy for systems change. I have called this journey:

'From Break Out - To Break Through'

## The 1970's

The system we wanted to change was legal and institutional - the advocacy was based on giving disabled people control over the finances that pay for personal care arrangements.

Until the 1970's all disabled people in the UK were either 'cared for' in residential institutions or at home by their families or social service home care staff'. That was until a small group of residents in a charity home decided they wanted to break out and live in a community. This small advocacy group, led by a man called Paul Hunt, began by asking for money that was financing their incarceration, to be paid over to them directly, so they could organize their own personal support.

As often the case with significant moments in history, when change is sparked off, it began with a direct challenge to the establishment. I think of the black civil rights movement and of Rosa Parks refusing to give up her seat to a white man!! For us in the UK the challenge to residential care and the State being our "Carers" came from Hunt when he wrote a letter in a National Newspaper inviting disabled people trapped in homes to join a self advocacy group to fight for change.

This was the beginning of the UK Independent Living Movement. A watershed: a handful of courageous individuals trapped in institutions developing a new way to live and sending out messages of hope. Advocacy in its purest form. Our heroes who took great risks in questioning the notion of institutionalized care. They wanted the money redistributed from the institution to the individual disabled people so they could take care of themselves. This was the beginning of the campaign for Direct Payments - that was to change the law 25 years later. A campaign where disabled people began to ask collectively for the financial power to change hands. The 1980's

The letter sparked "break-outs" - the most famous being Project 81- in a local region called Hampshire. A self advocacy gang of five disabled residents of Charity/social service home, who vowed they would be out living in the community, controlling their own care by 1981 - they started planning in 1977.

Not only did they achieve their aim but they developed and formalized their experience to the extent that it became a sort of blue print for other disabled people wanting independent



living. Thus emerged the first Center for Independent Living in Hampshire - HCIL, the body which was not only going to support disabled people in their struggle for Independent Living but which would begin the wider campaign for Direct Payments. HCIL had to demonstrate in very practical ways, how a whole new way of providing disabled people with personal assistance schemes. These new arrangements were and are challenging the historical relationship between providers of care and those who receive it.

#### Success in 1996

Employing and directing your Personal Assistance is indeed at the heart of Independent Living. For the disabled people's movement in the UK, the Direct Payments Act, which was "Born on the 4th of July", symbolically American Independence Day, is the realization of 20 years of collective advocacy.

Before the Community Care (Direct Payments) Act 1996, it was illegal for local social service departments to pay money directly to disabled people to purchase their own care. Personal assistance (care) was organized centrally by local/regional social service departments. They provided a home care service or regional care - thus the local authorities via professional staff were in control.

Now disabled people can choose to exercise that control by accepting a payment instead of a service, that they have been accessed as needing.

It is quite amazing to think it took 25 years for the Berlin Wall of institutionalized care to come down.

This fundamental shift in power - i.e. developed purchasing power - tested the willingness of those in the care business to really empower their so called 'client' group.

#### Lobbying for Legislation

Like other pieces of civil rights legislation e.g. the ADA, the Direct Payments Act was not easy to achieve. I was central to the lobby and took on the job of representing the mass of arguments and evidence coming from our disabled constituency. This was a difficult task because as a disabled woman I needed to be taken seriously by government officials who are predominately non-disabled men and I also needed to keep the confidence of the disability movement so that I could represent them powerfully.

I think I managed to satisfy both groups. What helped me enormously and why I think we achieved such a strong campaign, was because we were highly structured in our representations with Government officials and politicians.

When Paul Hunt began the first consumer group he stressed the importance of being 'consumer controlled and led'. We held true to that legacy as we built structures for representation and consultation throughout the Independent Living Movement. Thus, when it came to advocating our plans for Direct Payments Legislation, we had a national Independent Living Committee. All our regional Centers for Independent Living fed into that Committee with their views on what the legislation should address. I took my brief from the committee which gave me national authority when lobbying and working with the legislators. This process was tremendously democratic and supportive.

We worked from both within and outside. From within we joined the Government's Technical Advisory Group whose job it was to frame the law. From out side we lobbied with delegations, gave individual evidence and compiled research on the cost and administrative effectiveness of Direct Payments.

Our representations were so unified and well presented that any arguments against this Law were demolished, leaving the politicians and Social Care Professionals with little choice but



to accept defeat. To save face they termed it ' working in partnership with service users' and we have gone along with that as a political means to an end! In our hearts we know it was a victory for further control over our lives - I say 'further' as we are not there yet!

#### Implementation Stage

Once we had achieved the legal change, we moved fast to secure funding from the Government to set up a body to assist with the implementation stage. It was all very well giving disabled people the resources to control our own support, but without the information, advice and training to do it the legislation would set disabled people up to fail.

The Independent Living committee immediately submitted a proposal to the Government for a three year grant to establish a national center to provide the new support necessary to both disabled people and social services. As we had developed independent living infrastructures over the last 20 years we felt we were the best people to do the job. For once, the government agreed with us!

I'm happy to say the new Center is now established and is women led. All three workers are women. We not only work on the implementation of the legislation but support local and national groups of disabled people in contributing to the further development of national policy on community care. This form of advocacy has challenged the historical process whereby all policy was decided by medical and social care professionals. Now that disabled people have changed the system, there's no going back. This to me is advocacy for systems change at its best.

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#### Organizing for Legislation and Policy Development

Susan Chitimbe is the Executive Director of Disabled Women in Development in Malawi

In recent years persons with disabilities themselves have been in the forefront in providing an impetus for change and it is them, in their tens of thousands whose work has transformed the climate of public opinion to one of acceptance that disabled persons are entitled to live independent and dignified lives. Although this can be recorded as an achievement, the issue of legislation or policy making has remained an uphill challenge.

#### Mobilizing for Human Rights

The first strategy that has been deployed by the disabled persons has been to mobilize themselves into their own organizations to speak on behalf of themselves in National Assemblies and Regional Groupings in order to form unified forces of change.

They have also sought representation in their organizations that fight for human rights. In my country, my organization, Diwode (Disabled Women in Development) has formed linkages with other NGO's in order to advocate for disabled persons.

My experience has shown that it is imperative that disabled persons themselves be animated and educated on the issue of Human Rights so that they can be able to draw linkages between other human rights and their own disability issues which are also human rights issues.

Once disabled persons can fully grasp Human Rights issues,





they will, therefore, be well poised to lobby for equal opportunities legislation and also act as their own watchdogs so that, should legislation or policy be violated, they can be able to seek legal recourse.

This process is very difficult in Africa where the majority of disabled persons have been denied educational opportunities due to the negative attitude to which they have been subjected to since time immemorial. Therefore, the majority of them have not been able to progress beyond Primary School Education that is, those who have had the privilege of going to school. The situation is bad especially for women with disabilities.

In my country, human rights organizations, focusing on disability rights in the context of human rights in general have been formed in order to sensitize both people with disabilities and the general public on human rights and also to initiate legislation on equal opportunities. This will involve disability organizations, government and other NGO's.

#### Disabled Women in Development

While Diwode (Disabled Women in Development) will focus on economic development for women with disabilities it will also champion legislation on equal opportunities. It has already linked with the Council for Non Governmental Organizations and is also represented in the National Commission of Women in Malawi.

Organizations of people with disabilities have also formed an equalization of opportunities group to press for legislation in countries where it does not exist. I feel that disabled persons should utilize other existing resources to further this issue of legislation because these issues tend to be technical and, therefore, the most effective strategy is to deploy even able bodied technocrats who have been properly sensitized to fight alongside disabled activists.

Any policy or legislation without any back up mechanism is not useful. Therefore, as a conclusion, legislation becomes effective if the people concerned, people with disabilities in this case, fully grasp their issues and are to fully comprehend the legislation or policy.

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they will, however, be well served to look at the  
 organizational legislation and the way in which it  
 has been implemented in the past. It is not  
 to be taken for granted that the same will  
 be achieved in the future. The way in which  
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### The Right to Work

Susan Daniels, Ph.D., is the Deputy Commissioner for Disability and Income Security Programs, U.S. Social Security Administration.

First of all, I am delighted to have a chance to talk to you all this morning about work.

My first thought in talking to an audience primarily of women is we have to make something very, very clear. Women all over the world work. Raising a family is work. Taking care of a home is work. Taking care of sick children and aging parents is work. Doing dishes is work. Doing laundry is work. Paying the bills is work. Helping your children learn to read, holding them when they are depressed and upset, taking care of the emotions, the bodies, the health and the daily lives of a family is work. And so I honor all of the people here today that work at home to help make our society better by taking care of their families, by loving their children and by making home a hospitable, safe and growthful place for people.

Now, let's move on a little bit to the other kind of work that we are talking about today. Work where you get a paycheck. First, let me tell you a little bit about where we are in the United States when it comes to work and disability. Many of you



look at this country - I hope many of you look at this country - and say what a prosperous people, what a beautiful place, how lucky people are to live in a country where there is very low unemployment; and where people have opportunities to be part of the workplace even if they have disabilities. This is a great idea. Well, I think it is too.

### Work and Disability

But as much progress as we have made in the United States on certain issues, on the issue of employment of people with disabilities we have not made nearly the progress that we would expect. Let me give you a few statistics. More than 70 percent of the people with significant disabilities in our country do not have jobs. More than 50 percent of the people with disabilities who do not have jobs say they can work and that they want to work. Ten years ago (that's not long ago) we had 5 million Americans who were on cash benefit programs because they had a disability. Today, 10 years later, we have 10 million people on cash benefit programs because they are not working. Ten years ago we spent 30 billion dollars a year on benefits to individuals with disabilities who were not working. Today we are spending 70 billion dollars a year for benefits for people who are not working.

### Remarkable Changes

Now this 10-year period between 1987 and 1997 were years of remarkable changes in this country. In this period there were treatments introduced for all sorts of physical ailments that did not exist before. Twenty years ago when a person had a heart condition in the United States they often retired from work and went on benefits. Today most people who have heart conditions go in for surgery, leave the hospital in 4 or 5 days and return to work within 3 weeks. Because of the medical advances, most people with significant heart conditions in the United States are able to return to work promptly after surgery. In addition we have had remarkable changes in technology. I think you have had a chance to see some of that technology while you have been visiting. I certainly am a user of technology. I couldn't get around nearly as well without a scooter. I also use a computer and I use a program in my computer that lets me talk to it instead of typing. It listens to my words and types them on the screen. These are remarkable advances in technology that have made things possible for people with disabilities.

Another big change. In our country, people with disabilities now expect more and demand more. They want more opportunities and they say so at every turn. And finally, since 1987 the United States has implemented broad sweeping civil rights protection for people with disabilities. This is the same 10-year period where the first generation of young people in America who had access to free appropriate public education graduated from high school - a whole generation of young people who were included in public education. Let me ask you this question, ladies and gentlemen. If there has been so much improvement in medicine, technology, education and civil rights protection for people with disabilities why are more and more people unable to work? This is a question that I ask myself every day and I ask other people over and over again.

### Lessons Learned

In the United States we have the basis for a great economy that could include people with disabilities, but we have made some choices in our public policy that I would like to tell you



about. I'll tell you of the lessons that I have learned about why so many people with disabilities in our country are not working. Maybe you can avoid some of the pitfalls that we have fallen into and, in fact, make better programs in your own country.

The lessons that I have learned, I learned from experts. Those are the first people I talked to. Second, the people I talked to were people with disabilities. We went around the country and talked to our customers. We sat with them at independent living centers or in rehabilitation centers or wherever we could find them. Sometimes we talked to them on the Metro. We asked them the same question I just asked you. What's going on here? With so much opportunity why are so many people failing to find work and stay in the labor force? Here are some of the lessons that I learned from them.

First, while civil rights legislation is so important to establishing the basis for good programs and opportunity for people with disabilities, civil rights are not enough. Now I see the Americans' with Disabilities Act as unlocking the door. It's a key. The door was closed and locked and the Americans' with Disabilities Act unlocked the potential opportunity for people with disabilities; however, we must now make the effort to push that door open so that many more can go through it.

## Education

How do we do that? The most important lesson we have learned recently is that education is an absolute necessity. Now by this I don't mean education as just book learning - although that is important. But for people with disabilities education must also include the know how to get a job and to work in a labor force. This "know how" is sometimes taught in academic programs. Often it is taught at the foot of the master by learning from people who already know how to make a living and how to do that successfully. We find in this country that those individuals with disabilities who have an education and who have job training do very well in the labor force. Bad education and disability doubly disadvantage those who do not have access to education and training. The combination of a lack of access to education and accomplishments in education lead to very, very difficult outcomes for people with disabilities that include unemployment and poverty.

The single most important thing you can do for young people with disabilities is to be sure that they have the kind of education that will lead them to productive participation in employment. This is book learning in some places but often, it is just the plain "know how" that is learned from others who work in doing jobs that will help them earn a living.

## Low Expectations

The second lesson we learned is that we have, over a long period of time, institutionalized low expectations. Now what do I mean by that? I mean we have built systems that we call "special." The "special" bus takes the "special" children to a "special" school where they have a "special" class on "special" topics. Then they get back on the "special" bus and go back to their "special" place where they live a very special life.

## Special = Segregation

What's hidden behind the word "special" here is segregated. And we have been fighting over and over again in our country to take down that mask and recognize that separate is seldom equal. In fact, separate sends a message to young people that you don't





belong here, that you don't have a right to be where other people are and that there is something defective about you. This message is internalized over and over again by people who are subjected to "special" or "segregated" services. Now that doesn't mean that folks with disabilities should not get together, work together, help each other and learn from each other. But it does mean that coming together is voluntary and is based on expressed mutual interest.

This lesson that our customers have taught us is that we, in building this special system for everything that they do, have given them the message that we don't believe that they actually can participate fully in the mainstream. So many times we heard young people tell us that the adults in their lives don't expect them to do anything more than to make small objects in sheltered workshops and collect cash benefits for the rest of their lives. Young people who have internalized this message from the adults in their lives are at risk of living a life of poverty.

### Professionalizing the Ordinary

I've been watching this third trend for a long time myself. In fact, I think I participated in this trend. And this is what I call professionalizing the ordinary. I found it very interesting. The other day I was talking to somebody who was working in a field called horticulture therapy. Isn't it interesting that people with disabilities need "horticulture therapy" but other people just grow plants for fun? There is another activity called "equestrian therapy." People with disabilities have "equestrian therapy" but everybody else goes horseback riding. What we have often done in an attempt to try to help our brothers and sisters with disabilities is to make them into a professional problem that needs to be solved by someone who has very special training in a very special field. Now this professionalization is something that our independent living movement has tried to overcome. But I note this as a lesson that we learned.

People have often asked me "how do people get jobs"? Most people get jobs by knowing people who have jobs. Really! Think about that! Talk to anybody. How did you get your job? You knew somebody who already had a job, who knew about the job that you have now; or, you sat next to that person in church, or you met that person at some kind of function that was job related. Think of this for a moment. Why then, would you take whole bunches of people who don't have jobs and put them all together in a sheltered workshop. Is it likely they would meet anybody there who has a job? No. Here we have taken a perfectly ordinary problem (networking and meeting people who have jobs and know about jobs) and turned it into a special service for people with disabilities. The lesson we learn here is that the ordinary way to find a job or learn one is just fine. The ordinary way to have recreation and make friends is just fine. So I send this lesson out to all of you who are thinking about what is the best way to help people with disabilities in employment - and let me say it's the same way you would help anyone else. Challenge the Obvious!

Let me ask everyone here who did not have the foresight to bring his or her own chair to stand up. Some of you are still seated. I am not going on until you are all standing.

First of all, let's talk now about who has the special chairs. Who is at the advantage right now? Obviously, it's the people who brought their own. Aren't they smart and aren't they thrifty. Look at the rest of you who are standing now. Every place you go (you standing up people) you expect somebody to provide a little shelf that you can put your tushie on don't you? How much does that chair that you were sitting on cost? That chair costs about \$75. Oh, but that is not an accommodation is



it? Is that an accommodation to a disability? Well, it seems to me if you had to stand the whole time you were here you would be getting a little tired. You are starting to shift your weight right now. It's hard to just stand still isn't it? Stay standing, I'm not finished! Every place you go you expect other people to put a little shelf with a little back so you can rest your little back on it, so you can sit down. These cost \$75 each! Now, I brought my own, I never need one of those tushie shelves that we call chairs.

It's not just in this room that you expect that. You expect that in every room you go in. You expect that in the dining room, on the bus, on the Metro, in the theater. Every place you go, you expect someone to provide you with a place to sit down. You never say to yourself, do you, I wonder what it costs to accommodate my extreme verticalness? Do you? You never question that. You never say to yourself, what does it cost to do that accommodation because you don't question the obvious.

Let's talk about these sign language interpreters. Now that's expensive! Let's talk about expense for just a second. I am going to step back from the microphone and right now the interpreters can hear me just fine and they are communicating with other people in the room who are using sign language. Why are they so special and this microphone and PA system isn't? It's because you expect it to be here isn't it? And you don't run up to me and say "gee, it was so nice of you to put that special microphone there for me so I could hear you talk." But someone might say "isn't it great that they had interpreters at the meeting," because interpreters are special. But when you need to understand and hear this conversation it isn't. You're getting tired of standing, aren't you? Stay standing, it's not time to sit down yet. I want your feet to remember this as much as your head.

Let's talk about the rest of this room, these lights, for example. Now, you thought these lights were going to be on when you came in, didn't you? You don't like being in the dark, do you? I'm asking the Interpreter to step forward now. Here's a spotlight for you. How many miles of wiring does it take to put these lights in this room and run all of them to a source of electricity some 10 miles away? We have to wire the ceiling and the walls and install all of these fixtures. For what purpose? So that these excessively dependent visioned people could feel comfortable. If you all were a union of blind folks, we wouldn't have to do all this lighting. I've often said we could save a lot of money in the Federal Government if we only hired blind people because we could have a much smaller electricity bill.

You expect lighting, you expect chairs, you expect a very expensive accommodation to your ordinariness. You never ask the question "How much does it cost?" do you? Yet, when we talk about making things comfortable and easy for people who are different we have to talk about how much it costs. Well, I don't know how much it costs. How much does it cost to put an elevator in a Metro Station? I don't know. How much does an escalator cost? That's moving steps for lazy people: So I want to ask every one of you to recognize that to make an environment where everyone can function is expensive. It's expensive for the ordinary and it's expensive for the not so ordinary. We accommodate people without disabilities every day and never question that. We say it's just the stuff that they need. Well, I hope that everyone will think of the stuff that people with disabilities need is just stuff. So, on that note, let me say "lights up and all of you getting very tired folks, please accommodate yourselves to your verticalness."

## Conclusion

Ladies and gentlemen, we have to change the way we think. Accommodating human beings, giving them the tools and the



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## A Disabled Feminist on Sexual Politics

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### The Roots of Our Sexual Oppression

Disabled women are members of a sexual minority group. This means that we are not expected to reproduce, and that our ability to have children is considered a threat to our cultures. Because of this, we have been sexually and socially segregated, and prevented from having and expressing our sexuality of our own free-will. Sexuality and love has been the most painful parts of our lives.

There are myths about women with disabilities that can have a negative impact upon how we are treated as sexual beings by our different societies. Such myths also contribute to barriers to women's health services. Here are some examples:

- Disabled women are better off being served by disability specialists;
- Physically disabled women are asexual;
- Cognitively disabled women are over-sexed and have uncontrollable urges;
- Disabled women are dependent and child-like, and therefore need to be overprotected;
- Disability breeds disability, and therefore it is wrong for disabled people to parent;
- Disabled women should only have intimate relationships with other disabled people;
- If a disabled woman has a sexual problem it is a result of her disability;
- Disabled lesbians are with other women because it's hard for disabled women to get a man.

These stereotypes of disabled women create many barriers.

Disabled women and girls want information about relationships, sex, menstruation, pregnancy, birth control, sexually transmitted diseases, menopause and preventive health. But many of us never received key information, and are susceptible to misinformation about our sexuality.

One study found that none of the women with severe levels of physical impairment received contraceptive information from their providers. The group studied was comprised of educated activists, implying that less empowered women are even less informed. Another study found that disabled women have less knowledge of sexuality in childhood than their non-disabled peers because it was not discussed within the family; they did not receive health education in segregated special education schools; they confused menopause with signs of disability-related aging; and they believed that disability prevented vulnerability to





breast or cervical cancer.

Societies keep us ignorant and segregated because by:

"Keeping us genderless by discounting us as women and as sexual beings helps to prevent us from reproducing, which keeps us harmless to society. And, once we are categorized as non-breeders, we are discarded as socially useless and join post-menopausal women in health care limbo."

The absence of accurate information undermines our own ability to correct this political oppression of our sexuality. This must change by our advocacy efforts.

## Advocacy

Disabled women who are speaking about their sexuality today are opening up new doors for us and for future generations of women with disabilities. We are demanding that we no longer suffer from the medical management of our fertility. We are focusing attention on our rights to:

- Sexual Pleasure
  - Safe Women's Health Choices
  - Safe Pregnancy, Labor, and Delivery
  - Form Healthy Loving Relationships
  - Healthy Sexual Identities
  - A Rich Sexual Culture Within the Disability Community.
- To make sexual self-determination achievable by disabled women, real, long-lasting change must come from the grassroots. We disabled women must become our own sexual health rights advocates if possible, or have a good ally as advocate. The most practical way for disabled women to initiate any change, is by using our own life stories to force change. Every human rights movement started out this way. In the following discussion, six steps are suggested for disabled women to follow to make changes.

A first step is making the personal political. Sexual rights are human rights. Each of us has the human right to sexual activity, the right to have children, the right to be free of involuntary sterilization and abortion, and the overall right to control our fertility. These rights brings politics into our most personal and intimate spaces.

A second step in sexuality advocacy is becoming educated about our own health, and to know what we want for our lives. Listed in is a long list of books, articles, and organizations in the Disabled Women's Sexual and Reproductive Health Resource Packet ( available from Provider Services, California Family Health Council, 3600 Wilshire Blvd., Suite 600, Los Angeles 90010 USA; tel 213 386 5614). These resources can be used by women to learn more about our sexual health, as well as to get ideas for making future life decisions.

A third step in sexual health advocacy is to find other disabled women as sources of support. By finding other disabled women for support, we can learn about our true sexual potentials, needs, and desires. We can express our legitimate anger about the ways in which we have felt mistreated as women, and discover ways to mobilize our energies to make changes in our lives.

This leads us to a fourth step in our advocacy effort -- to direct our attention to the individual relationships we have with people in our lives. For relationships to work well, information must flow in two directions. Disabled women have a right to let people know who we really are and what we want for our lives. At the same time, women have a responsibility to describe what we need to meet our sexual goals for our future



happiness.

The fifth step involves changing women's health care from the inside. We already have expertise in health which we developed during the course of our lives. Also many disabled women are already doctors, and are other kinds of health providers, and work in social service agencies. It would be helpful if disabled women now worked in women's health to open the doors to other women.

Disabled women must begin to use our advocacy skills by demanding employment training to become women's health workers. Women with all types of disabilities from all types of cultures working in the system, is one of the most effective ways to make services accessible, respectful, and sensitive to other disabled women.

The sixth step involves changing women's health care from the outside. The non-disabled women's health services struggles with understanding or including disabled women's concerns in their programs. The disability community which is male dominated does not understand or include disabled women's concerns in its political agenda. As a consequence, disabled women all over the world are joining together to form our own political movement and agenda. It's just now emerging, mostly on a local basis in different cities around the U.S., and around the world.

Disability feminism is a new phrase, though it's still being defined. We are organizing to remedy our double discrimination, by drawing strength and strategy from both the women's rights and disability rights movements.

" In reality, the health issues of disabled women are in many ways more of the same concerns all women have. Often the obstacles we confront in obtaining health services are the problems of all women taken to the extreme. At other times, our needs differ from those of the rest of the women's community. Even when our needs are indistinguishable from those of our nondisabled sisters, the health experiences of disabled women are pertinent for all women and all health service providers."

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## Improving the Access of the Disabled People to the Labor Market in Brazil

Carmen Lúcia Fogaça is the manager of the Niteroi Association of People with Disabilities (ANDEF), Rio de Janeiro, Brazil.

### Introduction:

Preparing for the International Year of Disabled Persons as well as the Year itself (1981), brought to Brazil the deepest discussions of the issue of people with disabilities. Since then, the associations came to be directed by disabled people themselves, with the aim of struggling for the rights of the whole group.

Nevertheless, the most significant participation of people with disabilities in the process of struggle for rights in a country with little tradition of mass organization of social groups, due to a long - lasting military dictatorship have brought but a few lasting achievements to the movement. Without a significant number of militants, few goals were achieved on a practical level.

In response to this lack of mobilization, by the end of the 80's the associations had begun to search for alternatives which targeted the improvement of the lives of people with disabilities themselves. Thus, there came the first initiatives related to the offer of jobs to disabled people through contracts or subcontracts.

Our study about the theme acknowledges there are several



associations that have explored the alternative of directly providing jobs to their associates. This paper, however, considers research conducted in 13 (thirteen) associations, spread through 7 (seven) Brazilian States. In the State of Rio de Janeiro, 7 (seven) associations were researched, and also 1 (one) in Pará, 1 (one) Paraíba, 1 (one) Goiás, 1 (one) in Rio Grande do Norte, 1 (one) in Espírito Santo and 1 (one) in Rio Grande do Sul. Our concern was to provide a representative sample of our country as whole.

Another important point of information to be considered is that, at one point the mobilization of our movement was threatened by the prospect of changes in the National Labor Law (number 8.666/93), which deals with the process of hiring the work force. By sheer pressure, our movement has inserted an article in the text of this law, assuring that our associations, so long as they offer prices within the market range, would be free from taking part in the bidding process.

In addition to factors described above, our goal in this study was to describe the profile of the disabled female. Data such as age, civil status, schooling and wage average have been used to form this profile, since little is known about the Brazilian disabled worker. In this study, we intend to provide the first contribution to fill this void.

#### 1. Job Market and the Disabled Individuals

We affirm that the agreements established between private companies and the disabled peoples' associations have opened access to the job market and proved the efficiency and the capacity of these people in managing projects. In the associations researched, we have concluded that 1650 disabled people are working under these agreements (see Chart 1) and that the actual participation of disabled women (804) is 49% (Chart 2). This shows that the actual condition of the disabled woman, in this aspect, does not differ from the non-disabled woman, for both have been taking their place in the job market.

#### Entities Researched

##### Entities

	Workers
	women
	men
ANDEF	312
	124 (40%)
	188 (60%)
SADEF - RJ	193
	88 (46%)
	105 (54%)
ANFLUDEF - RJ	40
	20 (50%)
	20 (50%)
ADEFAR - RJ	12
	06 (50%)
	06 (50%)
CAIF - RJ	97
	60 (62%)
	37 (38%)
ASS.VALENÇA - RJ	09
	04 (44%)
	05 (56%)
CVI - RJ	





	58
25	(43%)
33	(57%)
APPD - PA	
	120
54	(45%)
66	(55%)
ADEFGO - GO	
	336
188	(56%)
148	(44%)
ASPADEF - PB	
	162
105	(65%)
57	(35%)
ACPD - ES	
	139
54	(39%)
85	(61%)
ACADEF - RS	
	106
41	(39%)
65	(61%)
ADEFERN - RN	
	66
35	(53%)
31	(47%)

chart.1

chart.2

## 2. Agreements in the state of Rio de Janeiro

We have today, in the State of Rio de Janeiro, seven associations of people with disabilities. These associations supply labor to Telecommunication Companies (Telerj), Electric Energy Companies (Light), Train Companies (Flumitrens), Data Processing Departments (Dataprev), the legal Assembly of Rio de Janeiro (Alerj), Water Transport Companies (Cedae), among others. These companies work with 721 disabled people, 327 women (45%) and 394 men (55%), as shown on Chart 5.

chart.5

In researching the agreements made by ANDEF - Niteroi Association of Disabled people, and comparing it to other entities in the State of Rio de Janeiro, we show that, from the total number of disabled workers, 312 are associated with ANDEF (Chart 3).

chart.3

## 3. Projects of ANDEF

ANDEF has been founded in August 1981, with the aim of organizing people with disabilities in Niteroi (a city in the State of Rio de Janeiro), so they could struggle for their rights. The first step in mobilization was sports activity. As with other entities, by the end of the 80's, ANDEF had signed its first contract with Telecommunication Companies of Rio de Janeiro,



for managing and operating telephone posts. Today, the entity is responsible for 12 service posts in seven cities of the state. In 1994, ANDEF opened the Industrial Unit called "Doing and Learning", its factory of crutches and wheelchairs, which are sold all over the country. In the same year, it signed a contract with Electric Energy Companies, in order to have public relation service, both in agencies and through the telephone.

In 1996, two new agreements came to improve the number of disabled people employed by ANDEF: one was signed with the Legal Assembly of Rio de Janeiro, for services of mechanics, electricity, painting, automobile-fender work, washing and shift work, among others. In September, another agreement was signed with Flumitrens, opening spaces to disabled individuals, as elevator operators and typists.

All these conquests actually happened with the change in the Bidding Law, an important advance for Brazilian legislation. As can be seen on Chart 12, while ANDEF had, until 1993, only 111 clerks, with the introduction of this law, it witnessed an improvement of almost 100% in one year, definitely bringing disabled woman to this context. Today, ANDEF employs 312 disabled people in its five agreements, in the administration section and in the sports area (Chart 4). Disabled women occupy 40% of these places.

chart.12

chart.4

Another interesting point is the presence, in larger numbers of workers - men as well - between 20 and 40 years old (Chart 6), that is, young adulthood. As we take age as a parameter, we may prove that disabilities make no difference, but, in comparing within male sex, we prove that men keep regularity at work, improving their presence as they grow older (Chart 10). Concerning civil status, we have found out that the biggest share of these workers are single (Chart 8), men as well as women. After that, come married people and a small percentage of divorced and widowed ones (Chart 9).

chart.6

chart.10

chart.8

chart.9

Concerning schooling (Charts 7 and 11), data show that 35% of people with disabilities do not access basic education, not having spent at least nine years at school. The largest demographic group is of clerks with High-School education, about 55% of total. This confirms that, by and by, the job market demands qualified workers. Thus, the highest number of places, for men and women, is offered to the last group mentioned, where the disabled individual spends at least 12 years at school. This tendency and the demand of the job market, however, is worrisome to the movement of people with disabilities, mainly when taking into account their lack of access to schools, ranging from lack of vacancies to lack of proper physical access. Thus, we come to



know that a significant percentage of this group has not managed to enter formal job market, and probably never will. Also important is the number of disabled people with a college degree: only 10% reach university , meaning they must have spent at least 16 years at school.

chart.7

chart.11

Concerning wage average (Charts 13 and 14), we have 86% of employees receiving between 1 and 5 minimal wages (between US\$ 112,00 and US\$ 560,00), and 37% of them are women. In the average of 5 to 9 minimal wages (between US\$ 560,00 and US\$ 1008,00), we have 10% of employees, and 1% of Women. Between 9 and 15 wages, we have 3% of employees, only one women among them (that is, less than half percent). Above 35 wages, we have 1%, all of male sex. This shows that, although the disabled woman is inserted in the job market, through contracts, she still fails to occupy high positions, and so her salary is not the same as men's.

chart.13

chart.14

#### Credits:

This work was made for Carmem Lúcia Fogaça, with collaboration of Carla Angélica dos Santos Paula, Kátia Carneiro, Geisa Maria Gomes Campos, Ricardo Inácio, João Batista Carvalho e Silva, Rubens Emerick Gripp, Cleomar S. Vieira Couto and Lilian de Azevedo Nunes.

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Public Education & Health:  
How to Approach Disabled Women's Issues

Rina Gill was, at the time of the Forum, a social communication specialist for UNICEF Bangladesh in Dhaka. She is now the UNICEF Resident Representative for Maldives.

The focus of my discussion will be limited to the experiences I have had in the field of social communication and the manner in which we project images of people with disabilities in our public service communication campaigns - particularly in the area of health education. If time allows, I will share a few ideas on how some of the lessons learned from working in the area of disability prevention can be applied to the issue of women with disabilities.

Reaching Beyond the Converted

The issue of presenting positive images of people with





disabilities in the media has been the focus of discussion and action by activists working in the field of disabilities. Conferences such as this one abound with powerful and inspiring examples of people with disabilities as leaders of society, as professionals, parents, advocates, artistes... but how many of the participants come from any field of work unrelated to disability? In particular, how many non-disabled participants do we have from the fields of public health, basic education, from commercial corporations or the mainstream media? My fear is that in being so exclusive, we run the risk of preaching to the converted and thereby exclude a very large and influential body of people whose work affects our lives almost every day and who are, therefore, dealing with the issue of disabilities albeit in an indirect way.

By way of an example, for several decades, tens of thousands of people have worked in the field of preventive health. Their numbers are far greater than those of people working on disabilities projects. More importantly, perhaps, they reach and influence hundreds of millions of people globally through a massive network of primary health care projects. How do these health professionals and frontline workers perceive people with disabilities and what attitudes do they in turn communicate to millions of households around the world?

Each year globally, hundreds of millions of US dollars are spent on public health projects aimed at the prevention of polio, vitamin A deficiency blindness, iodine deficiency disorders and other such disabilities. Invariably, several million dollars are allocated to the public information campaigns that accompany these projects. Almost without exception in each of these campaigns, even today, people with disabilities are portrayed as helpless, hopeless, totally dependent on others, isolated and a burden to their families and communities. For example, a few years ago a poster produced by an international NGO urged people to eat green leafy vegetables to prevent vitamin A deficiency blindness. The main caption of the poster stated, "It is better to be dead than to be blind."

Let me hasten to add that the people who plan and execute these campaigns are not necessarily insensitive or uncaring. In many cases, their commitment and professionalism would be an asset to any project.

Why Does This Happen?

Why, then, does this happen and what can be done to prevent or correct it? Perhaps I can share a personal example. In the mid-eighties, the Government of India launched a nationwide child immunization program aimed at preventing childhood diseases such as tetanus, measles and polio. A critical component of this program was a massive public education campaign aimed at creating awareness regarding the importance of immunization. A behavioral research study was immediately commissioned to form the basis for planning the communication strategy. The results of the study indicated that mothers who had actively sought the immunization services i.e. those who had traveled long distances and gone through considerable trouble to get their children fully immunized, were aware of the fact that without immunization, their children could be disabled or die.

As communicators, we immediately concluded that in order to spur people into action, we had to convince them of the disastrous impact of having a disabled child in the family. The primary strategy was to use fear as the motivation for action. We therefore sought and projected some of the most de-humanizing images we could find of people with disabilities. The message was clear and consistent: immunize and protect your child against crippling and fatal diseases. The campaign was simultaneously released on national television and radio, and through the press and printed media, thus providing us access to over a 100 million households. The results were predictable: people flocked to the



health centers to get their children immunized.

### New Beginnings

It was only after several months, after a chance encounter with a disabilities and media specialist, that I realized the full impact of our negative, fear arousal strategy: despite our good intentions as far as child health were concerned, we had unwittingly also communicated and reinforced all the negative stereotypes that exist of people with disabilities being worthless, unwanted and a burden.

I was ashamed. Determined to correct the error, I started advocating for the positive portrayal of people with disabilities in our preventive health campaigns. My efforts met with little success. Program managers were sympathetic but reluctant to jeopardize multi-million dollar projects on the basis of a moral or ethical argument. After all, they felt, what were the sensitivities of a relatively small number of people compared to the "greater good" of the millions? Second, there were no models or prototypes available of health education materials which used a positive approach. "What do you want us to say?" asked one internationally renowned public health expert, "Your child has polio, Hurrah! Hurrah!?" Third, there was no research or empirical evidence to prove that positive images can and do work.

### Time to Produce Prototypes

It was time to produce prototypes and test their effectiveness. Since polio was the most visible of the vaccine preventable diseases, we produced a series of both positive and negative public service (television) advertisements (PSAs) in Nepal. The negative PSAs used the stereotypical approach of treating the disabled child as the object of pity. The positive PSAs used people with polio talking about themselves and urging people to get their children immunized.

The PSAs were screened and pre-tested in 14 Focus Group Discussions and through over 220 individual in-depth interviews. The results indicated that both the negative and positive PSAs were equally effective in conveying the desired information and that audience recall was high. The difference, however, emerged when we asked the respondents what they felt they should do after seeing the advertisements. Respondents who had viewed the negative PSAs were more fatalistic: "We can't do anything now. This is God's will." However, respondents who viewed the positive PSAs said that they would ensure that the children in their community were immunized. We then asked the respondents which character they liked the most. Those who had viewed the negative PSAs selected a non-disabled person while those who had viewed the positive PSAs selected the disabled person because they felt he or she was socially responsible, helpful and giving valuable advice. Finally, on being shown all the positive and negative PSAs, the respondents were asked to select their favorite film. An overwhelming 80 per cent selected a positive PSA.

### Lessons Learned

What are some of the lessons we derived from our rather modest experiment? I will select just three:

- (1) Allow people with disabilities to talk for themselves - do not talk about them;
- (2) Portraying people as the victims or as the problem robs them of their dignity and self-esteem. Seek examples of good practice and good role models among people with disabilities and



allow them to present the case.

(3) Integrate people with disabilities into all media and materials - commercial, public service, even school text books. Just producing a few disability-specific materials will not solve the problem because they will be overwhelmed by the other 99 per cent of the media to which we are exposed each day and which are full of images of Barbie-doll women and athletic men. We must increase the visibility of people with disabilities in all our mainstream media and activities, just as we have started increasing the visibility of other marginalized groups such as girls, women and ethnic minorities. Visibility will lead to familiarity. Familiarity to a feeling of comfort, and comfort to acceptance and partnership.

### A Life Threatening Condition

More specifically, what lessons can we derive for our work on the issue of women with disabilities? I come from South Asia - a region where to be born female can, in and of itself, be a life threatening condition: in India, pregnant women undergo sex determination tests and are routinely forced by their families to abort female fetuses. A study conducted in Bombay revealed that of the 8,000 abortions undertaken in a clinic, 7,999 were those of female fetuses. Girls who survive are socialized into accepting and expecting less than their brothers: less food, less health care, less education, less consideration, less affection. In the absence of alternative role models, the average South Asian girl grows into a woman with low self-esteem and without the ability to question or challenge her condition. She in turn transmits her sense of worthlessness to her daughter. A vicious cycle is thus perpetuated from generation to generation. If and when she receives any attention from policy makers or service providers, it is in her role as the bearer or caretaker of children. "Invest in a woman and you invest in a family," says the World Bank - implying perhaps, that a woman is not worth anything in and of herself.

Add to this the additional problem of a disability and you have a triple jeopardy: female, poor and disabled - the perfect recipe for a South Asian disaster. It remains a fact even today that disability in a girl or a woman is often considered a fate worse than death.

### What Lessons Can We Apply?

What lessons should we seek to apply for promoting the cause of women with disabilities? The points regarding disabled women talking about themselves and being portrayed as positive and strong role models are obvious. I would like to underscore the point about integration, mainstreaming and higher visibility in the media. Perhaps the most valuable gift that we take back from this Conference is the power of knowing that we are not alone. Millions of other disabled girls and women around the world desperately need to feel the same power. The potential of the global communication media needs to be harnessed and exploited.

Second, let us learn from other global movements and experiences. When the nations of the world embarked on the ambitious venture of immunizing the world's children, the rallying cry was that health was too important an issue to be left to the health professionals alone. As a result of the global mobilization, hundreds of millions of children were immunized. Civil wars were stopped on the day of immunization to create corridors of peace so that children on both sides of the conflict could be reached. Our experience from the women's movement has demonstrated that strategies of exclusion and reverse discrimination are counter-productive. I now venture to



say that the movement for women with disabilities is too important to be left in the hands of women or disabled women alone. Let us co-opt partners from the fields that constantly intersect our lives: from the health and education sectors, from industry and from the media.

And finally, as a non-disabled woman I say: please let me in. Please teach me to understand and appreciate you, and please allow me to walk with you - so that together we can realize our most ambitious dreams and aspirations.

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## Education: Engine of Empowerment

Judith E. Heumann is the Assistant Secretary of Education, Office of Special Education and Rehabilitative Services, U.S. Department of Education.

My own point of view starts with the idea that education is the main engine of equality and empowerment. And that having high expectations for disabled students is the main engine for gaining excellent educational opportunities.

Secretary Riley discussed the Individuals With Disabilities Education Act of the United States, - the IDEA - which today guarantees equality of educational opportunity for disabled students as a matter of right ... a civil right.

Well, I went to school long before the IDEA became law. I was among the more than 3.5 million American students with disabilities who did not receive adequate schooling. Actually, more than one million disabled children were not receiving any public education at all.

I developed polio when I was one and a half. When it was time for me to go to school, the school officials did not see me - they only saw my wheelchair. And they barred me from class. I was a fire hazard, they said. The message from the school system was clear: society assumed my future was worth less than that of other children. Well, it was pretty easy for them to push around a kindergarten kid, but my mother was something else again. She is one of the toughest kinds of woman you'll ever meet - a housewife from Brooklyn, New York. Without experience, she and my father became activists and my strong advocates. They joined the ranks of hundreds of thousands of others in the movement for disability rights. And I finally did get my education. Thank you, mom.

Years later, when I applied for my teacher's license, the Board of Education of the City of New York refused me again. I was still a fire hazard. But this time I could fend for myself, and the disability rights movement was gaining strength. I sued them. And I got my license, and taught elementary school for three years.

Let me make this clear: in the United States, disabled students were more often than not denied good schooling until disabled people joined with their allies and won the right to an appropriate education for all.

I benefited from their victories. I received a good education. And because I received a good education, I had the opportunities to achieve. Today, I am a ranking political official in the U.S. government working for President Bill Clinton.

## Success in 1995

Because of the world-wide disability rights movement, we have come a long way in a short time. Nine years ago, Evincia Edwards of St Kitts, a blind single mother who was then 25 years old,



summed up the global situation to me when she said, "We don't get much response from society." But two years ago, in Hairou and Beijing, we won a tremendous response from the international Women's Movement! And, thanks in part to the strong allies we made within the Women's Movement, we are able to hold this Forum. To me, the most profound significance of this Forum is that it signals that the issues of disabled women are truly integrated into the Platform for Action of the Fourth World Conference on Women - the main product of the 1995 Beijing Conference.

#### Education as Right

Among other things, that platform calls on the peoples of the world, and the governments of the world, to intensify efforts to advance the goal of equal access to education by taking measures to eliminate discrimination in education at all levels on the basis of gender, race, or disability! This is a clear statement that equal access to education should be ours as a matter of right, not privilege. Being included prominently in the Beijing Platform for Action is a significant victory, but we all know that it will remain just a paper victory unless we work every day to make the words come alive and to make the goal of full equality come nearer. We are here today because disabled women still rank at the bottom of every scale that measures progress. Recent studies show that disabled women are among the least likely people to be employed, the most likely to live in dire poverty, and among the people most likely to die young!

We are here today because disabled women still rank at the bottom of every scale that measures progress. Recent studies show that disabled women are among the least likely people to be employed, the most likely to live in dire poverty, and among the people most likely to die young! Studies have shown that strong networks, both national and international, are needed to enable girls and women with disabilities to support each other in their efforts to live independent, productive lives. But creating a world that facilitates and nurtures the contributions we can all make takes strong programs underpinning the networks.

#### Poverty and Illiteracy

Lack of educational opportunities is both a cause and an effect of poverty and discrimination, but we can make discrimination against disabled women a dim historic footnote of the past by creating equal educational opportunities in the future.

? One of the reasons that disabled women are among the poorest of the poor is because some 65 percent of the world's women are illiterate. In Africa, that rises to 85 percent.

? One of the reasons that the percentage of disabled women in the work force is so low is because only 1 to 2 percent of disabled children in developing countries receive any education at all, and it is well-known from field studies that disabled boys attend schools much more frequently than disabled girls.

? And one reason that disabled girls receive less care than disabled boys is that there are not enough disabled women with sufficient education to act as advocates for disabled girls.

In other words, while education is an important link to the future for all people, to disabled people getting a good education can be a matter of survival. Indeed, a 1994 conference on "Blind Women in Africa" presented information from 32 countries that demonstrated that access to literacy programs and education was often their only way to avoid



a life of begging in the streets.  
 However, even in the wealthiest countries, disabled people have often had access only to inferior education.

#### Platform for Action

The Platform for Action from the Beijing Conference calls for the creation of universal access to basic education by the year 2000, for the elimination of the gender gap in primary and secondary school education by the year 2005, and for universal primary education in all countries before the year 2015.

We must work - and work every day - to ensure that disabled students - both girls and boys - are included in plans for meeting these goals.

? The Platform for Action calls for collaboration between parents, communities, educators and business to ensure universal education for all. We must make sure that parents of disabled students are included.

? The Platform for Action calls for career planning, leadership and social skills to be included in girls' education. We must make sure such training and education includes disabled students as well. When I was a student, I received virtually no career counseling because it was generally assumed that disabled people could have no significant careers outside of sheltered situations or medical settings. What a waste of human potential that kind of thinking was!

? The Platform for Action calls for sufficient resources to be allocated for the accomplishment of educational goals. We must make sure this includes the technological devices and learning supports disabled students need to succeed.

? The Platform for Action calls for better training for teachers. We must make sure that all teachers are sufficiently trained to serve the needs of disabled as well as non-disabled students.

? And the Platform for action calls for the creation of teaching materials that show the contributions of women. We must make sure teaching materials also show the contributions of disabled persons.

#### Learn from Other's Mistakes

I urge you all, as your nations develop their education policies, learn from the mistakes of my country, the U.S.. For example, when we built most of our public schools, we did not build them to be accessible to disabled students. That was an expensive mistake. Today, we are having to rebuild all our schools to accommodate disabled students. It would have been much cheaper for us to have built our schools accessible in the first place. As your nations develop their education policies, please recognize the grave error of creating segregated school systems. We created separate schools for the disabled in the United States because it was generally felt that disabled students could not learn to the same high standards as other students. Today we know better. Today we know that every student can learn - disabled or non-disabled.

#### Results of U.S. Law

For example, since the disability rights movement won the passage of the IDEA, the percentage of students with disabilities who graduated from high school or received a completion certificate has risen from 55% in 1984-85 to over 66%. And more than 44% of college-age disabled students attended at least some postsecondary education in 1991-92, up from just 29% in 1984-85.



To win laws similar to the IDEA around the world, we must continue doing what we have been doing: building a strong world wide disability rights movement, building strong alliances within the Women's Movement, and within the union movement, and within the movements for civil rights for all in every nation on earth.

#### Self-Esteem

A strong Disability Rights Movement must be based on people who have a feeling of self-esteem. With self-esteem people can feel they have rights and deserve to have rights. People can get angry and do something about it. But too many people with disabilities most of their lives have fallen victim to a system that is paternalistic at best and treats them as charity cases, or is cruel and arbitrary at worst and ignores both the existence and potential of people with disabilities.

But we know the truth. Being disabled is just a way of being. It's: natural ... healthy ... normal. Or at least it could be for most people if they had the resources and supports they need. Understanding this fact is the beginning of building the self-esteem it takes to build a movement that speaks up for disabled people.

#### Role Models

And the willingness to speak up effectively takes pride. To build this pride, it is vital that disabled students meet disabled adults who are engaged in a wide variety of professions and roles.

I know the importance of role models from my own experience. I don't remember meeting anybody else with polio until I was 10 or 11. When I became a teacher and taught a classroom of disabled children, I was the first disabled teacher those children had. That was then. This is now. Hopefully today, we can all help disabled children - and adults - build pride in themselves.

#### Conclusion

Together, we are strong and growing stronger every day! The fact that we were able to organize this Forum shows that what anthropologist Margaret Mead said so many years ago is absolutely true today:

"Never doubt." she said, "that a small group of thoughtful, committed citizens can change the world; indeed it is the only thing that ever has."

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Communication - The Basis of Our Liberation Struggle

Rachel Hurst is the Director of Disability Awareness in Action, United Kingdom.

More than 15 years ago I was at a meeting at a special school for disabled children to discuss the inclusion of disabled children into mainstream education. One of the educational professionals there said that you could not include children who could not communicate. I immediately said: 'Why cannot they communicate? Are they dead?' This response was not received very well - but it highlights what I believe is the real truth - everybody can communicate, the problem is that many people can not understand what is being communicated.

Many people think that a human being's ability to communicate with another through sophisticated speech patterns is what separates us from animals. Our speech patterns may be sophisticated but often our understanding is not - nor is our



ability to use our communication tools effectively. But what we all share is our dependence on communication - it is as important to us as breathing, and the information that we either give or receive is as important to us as food. We cannot survive without it.

### Denied Information

When I first identified as a disabled person my greatest need was not for ramps to my house or a wheelchair but information about my new life. I wanted to know what were the possibilities, what were the choices I had. Non-disabled people have information about their lives readily available to them. They are informed by their families, by their communities, by the media, by their shared culture - all this information reflects the sorts of lives that they live and gives them an understanding of how they as individuals fit into this overall informational picture.

As disabled people, we have been denied this information. Our families generally do not know what to tell us about our lives, or have their own, generally very low, expectations of our role in the family. Our communities often do not know how to talk to us at all, let alone include us in the general information giving. The media have such stereotyped views of us that they only see us as either tragic but brave, overcoming the odds to become heroines or champions, or as pathetic and powerless objects of charity. It seems that the only things that are newsworthy about us are our impairments, the length of time we have 'endured' our lives and whether we are properly grateful for the care we receive, if any. If we are depicted in our culture it is always in this stereotypical way. There is nothing better than to make the bad person in a story, film or play, a disabled person. How much more frightening it is if the witch, or the gangster has a crooked spine or has lost a limb. So we have a double problem here. Not only are we, as disabled people, denied information that is relevant to us. Up until very recently, information on disability issues that has been communicated has had a very serious effect on the way other people see us.

### Tools of Oppression

This use of negative, passive images in communication is a well-known tool of oppression - one that has been used against women and people of different ethnic origins for a very long time. How well we know, as women, that we have for so long been portrayed as wives or mothers, powerless, unpaid servants to our fathers, husbands, brothers and lovers. If we are given power, it is generally confined strictly to the family circle and does not extend to economic or political power. Every country and tribe uses similar negative communication methods when they are trying to show how much better they are than a neighboring country or tribe. In England, for instance, there are endless jokes made about 'A Scotsman, an Englishman and an Irishman' who are doing different things or who react differently. These jokes always portray the Scotsman as mean or cheap, the Irishman as stupid and the Englishman as the only one who is clever. I am sure you all know similar examples. Please note that these jokes are always about men - again giving the message that women are not really Scots, or Irish or whatever!

### Negative Response to Difference

What is really happening is that we are all communicating our negative response to difference. We are saying that anything or



anybody who is different from our accepted idea of who should be part a particular group should be excluded, mocked and criticized. And we are not just negative about our images of people who are different. We make sure that we communicate in a way that makes people who are different unable to hear or understand what we are communicating. It may be by using language in a way that keeps out people who are not the same as us. Professionals are particularly good at that sort of communication trick. Whatever the profession, they assemble a vocabulary that only they know and for which most other people use much simpler words. This is quite understandable when they are communicating among themselves. Scientists would be expected to communicate to other scientists in their professional language, but sometimes when they are trying to show how clever they are, or more importantly how uninformed the person is to whom they are communicating, then they use this scientific language to disempower. I am sure nearly every one of us has sat with a doctor or health professional and wondered what they were asking us because they used words which we did not understand and we were too frightened to show our ignorance. Aid and development workers have also gathered their own language around them, which can again make those people they are specifically meant to help feel even more powerless. For instance they often talk about getting a group of people together and doing 'animation exercises'. To me that sounds as though they are bringing cartoons to life - just as in animated cartoons on film. That is a very patronizing way of speaking about people. Why could they not use words like 'help' or 'share experience' or 'develop'. By using professional words the speaker implies that they are the ones in control and the others are not.

To put all that I have said so far in simple terms: communication is essential to our well-being and information must be appropriate and given in a facilitating way. We have to struggle against the damage that oppressive and negative messages can do to further exclude us from society and prevent our equalization of opportunities.

So What Are We, Disabled Women, Going to Do About This?

? First and foremost, we have to share our information. We have to communicate our experiences and knowledge with others. We should not feel that the duty of communication can be left to others, each one of us has a responsibility, even in a private and quiet way, to pass on the enabling information we have. And we have similar responsibility to take in information, to demand the right to information, even if it is only chatting with other disabled women and sharing experiences. In fact that sort of communication can be the most empowering of all. The world wide movement of disabled people was started when disabled people from different countries met at a barbecue and through talking with each other recognized how much they shared and then decided to do something about it.

? And when we communicate we should do it with every one we can. Just as we feel angry and disempowered because we have not been informed, so we should ensure that we are not excluding people from our little seed-bed of knowledge.

? We also need to responsibility for ensuring our organizations do the same. If, for instance, you are a group of blind women, it is important to share information with women who have different experiences. It is important to find a way to overcome barriers of communication, to find ways of sharing information with people who do not use speech or whose language is different or whose experiences and views on life are very different.



? One of the problems for us disabled women is that disabled men keep us out of taking an equal share in the development process, but how can we get disabled men to understand our double discrimination if we don't tell them about it? Similarly, professionals are never going to understand that disability is about social change and inclusion if we do not tell them.

? We have to ensure that our organizations also communicate with policy-makers and governments. The information we have about ourselves and that we have shared - must be part of the policy-making process and be at the fore-front of all legislation, especially non-discrimination legislation - that directly affects us.

? And last, but by no means, least - we must strengthen the lines of communication with the media to ensure that they stop the negative and stereotypical images of us and provide us with appropriate role models. When our policies and rights are being discussed it should be us that are leading the discussions. When women's issues are being discussed disabled women should play a role in those discussions. When development issues are being discussed disabled people should be there, our voice heard loudly and clearly. 'As Disabled Peoples' International has said for many years - 'Nothing about us without us'.

#### Conclusion

This all sounds like hard work - all this communicating and sharing. And it is. Changing our lives, empowering ourselves cannot be done by sitting down and doing nothing. Communicating our experiences, our needs, our hopes and our rights is the foundation of all that we do to liberate ourselves. Of course we are not always going to get it right. The message does not always come across as we want it to or is not received properly. I can only hope that from this effort of mine to communicate about communication, you have got a little feeling for the passion I feel about the subject. How deeply convinced I am that communication and information are the basis of our liberation struggle - our liberation struggle both as women and as disabled people.

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Community Organizing:  
KAMPI's Experience in Philippines

Venus M. Ilagan is the President of Katipunan ng Maykapansanan sa Pilipinas, Inc. - KAMPI (Federation of Persons with Disabilities), Philippines.

Brief Background of KAMPI

The Katipunan ng Maykapansanan sa Pilipinas, Inc. (KAMPI) is a federation of Self-Help groups of Disabled Persons in the Philippines. Its aim is to work for the improvement of the lives of persons with mental, physical, and sensory impairment.

Established by the Second National Congress of Persons with Disabilities (PWDs) in July 1990, KAMPI's founding was both a response to the formal recognition by the Philippine government of Persons With Disabilities as a legitimate sector of Philippine society and the need to create a national organization of PWDs. KAMPI seeks to create a strong voice in pushing for the implementation of programs and policies that will promote the



welfare and ensure the productive integration of PWDs into the mainstream society.

KAMPI is actively involved in organizing and empowering PWDs not only to be part of the mainstream society but at the same time become members of their communities. It is guided by four major concerns of the sector, namely, genuine accessibility, integration, equal opportunities, and poverty alleviation.

In 1993, KAMPI was awarded the title as the Best NGO of the Year by the Philippine Government besting NGOs of long and outstanding track records. Although relatively young as compared with other NGOs, KAMPI has successfully carved out its niche in the field of advocacy on disability awareness.

Since its inception, KAMPI has expanded its network from 11 chapters in seven provinces to 176 chapters in 58 provinces, 17 cities, and 73 municipalities. Today, KAMPI has 204 member-chapters all over the Philippines with more than 10,000 strong membership in the grassroots level. Notably 55% of these members are women. KAMPI, with this number, can be considered as one of the biggest, and possibly the most active Self-Help organization in the Philippines.

KAMPI adheres to the policy of full participation and mainstreaming of persons with disabilities in every aspect of life. To achieve this, KAMPI has been organizing and strengthening self-help grassroots organizations to empower persons with disabilities to determine, choose, and have control over services they need to be integrated into the mainstream of society and live independent lives.

KAMPI's mandate is to advocate for the needed changes in society's prejudicial attitudes, policies, and practices towards disabled persons for the country to achieve a "society for all".

Over the past six years since its inception, KAMPI has set out to undertake projects for the benefit of Persons with Disabilities. With its limited resources, KAMPI sought assistance from its partners both local and international, to fund projects envisioned to assist Persons With Disabilities. In the course of its endeavor, KAMPI has successfully undertaken various projects benefiting Persons With Disabilities. To this day, these projects continue to exist despite a limited financial budget.

Projects being undertaken by KAMPI vary from small-to-medium livelihood projects for grassroots disabled persons to training and wheelchair production. Its biggest and well-known project is the Stimulation and Therapeutic Activity Center for children with disabilities.

#### The Relevance of Community Organizing to KAMPI's Programs and Services

Community Organizing is a critical component of KAMPI in enabling Persons With Disabilities to become active and productive members of Philippine society. Community Organizing, therefore, is one of KAMPI's primary strengths. It should be noted that most of KAMPI's grassroots leaders and members are well-trained and highly-skilled community organizers working extensively in the area of advocacy and awareness.

##### Definition

- Community Organizing is a problem-solving approach whereby the community is empowered with the knowledge and skills needed to identify and prioritize its needs and problems, harness its resources to deal with these problems and take action collectively (1).
- Community Organizing works towards the empowerment of people to determine their development and shape their own future, leading to the active and collective participation of people in development work.



For its part, KAMPI has institutionalized key elements for effective community organizing. These elements are a combination of practical ways/means of basic organizing and knowledge on disability issues. However, KAMPI believes that these are not the only ingredients of effective organizing. Crucial to the matter is the understanding of culture and working dynamics endemic in local communities. The understanding of these makes organizing easier to undertake and becomes advantageous to the community organizer.

To underscore this relevance is KAMPI's current endeavor, the Stimulation and Therapeutic Activity Center (STAC), a project that necessitates a continuous process of organizing and networking, .

The STAC project is a nationwide undertaking that provides free and comprehensive rehabilitation and therapy for children with disabilities. At present, it caters to more than 300 clients all over the Philippines.

Over the past two years, the concept of STAC has evolved into a more comprehensive source of free rehabilitation and therapy treatment for disabled children and has added significant features, i.e. livelihood assistance for parents, provision of assistive devices, etc. Other significant components include the Parents' Training Program which became instrumental to the operationalization of Satellite STACenters in cluster baranggays.

The Parents' Training Program is a KAMPI initiated concept which is an offshoot of the Community Based Rehabilitation (CBR) program espoused by the World Health Organization (WHO). The PTP, as is widely known, is a home-based training program of basic rehabilitation and therapy techniques which facilitates the rehabilitation process of a disabled person through the active participation of parents and family members. It is at this juncture that community organizing becomes an indispensable ingredient and, more importantly, a significant source of KAMPI's promising programs and services.

#### KAMPI'S Major Steps in Community Organizing

- Identifying the sector's common needs which includes opportunities, threats, strengths and weaknesses;
- Identifying existing programs or services that cater to the needs of the sector;
- Mobilizing the sector to act together and come up with alternative responses to fill gaps in the existing programs and services;
- Networking/coordinating with existing program/service providers;
- Building the sector's associations to become self-sustaining.

#### Some Obstacles to KAMPI'S Community Organizing Endeavors

Inherent to organizing Persons With Disabilities is the difficulty in reaching out to those living in far-flung areas. Foremost, organizing People With Disabilities is never easy especially for a country like the Philippines. The Philippines is comprised of more than 7,100 islands and has more than 100 languages and dialects. For this reason, organizing becomes a major challenge especially for a disabled person acting as an organizer.

KAMPI, in its long years of service to Persons With Disabilities, has listed the following obstacles to an effective community organizing:

- Lack of financial support: Most KAMPI members do not enjoy financial assistance in their community work.





- Lack of cooperation among NGOs, self-help groups, and Local Government Units, and other agencies: This problem dampens the initiatives of PWDs to organize.
- Poverty: Majority of KAMPI members are poor and have no financial resources. Also, unemployment is high in the sector due to very limited employment opportunities.
- Persons With Disabilities in the grassroots more often find no time to participate in development work: Most KAMPI members are preoccupied with their livelihood activities that they no longer have the time to participate in development work.
- Majority of the people in the grassroots lacks educational background in understanding the importance and processes of social development work: the majority of disabled persons in the Philippines are illiterate. Only a few disabled persons have gone through regular schooling.
- Resistance against women community organizers: Women with disability suffer severely from adverse public attitudes and prejudices.

Despite these obstacles, KAMPI has been very active in pursuing its community organizing endeavors. Because of this, the national government has become aware of the needs of the PWD sector. As a result, the government recognizes now the developmental implications of disability and the need to implement support measures aimed at improving the welfare and participation of Persons With Disabilities in the context of national development goals and processes. These vocal pronouncements of the government has made community organizing easier to undertake by disabled persons. Further, it should also be pointed out that the government of President Fidel V. Ramos has undertaken initiatives to assist marginalized sectors of Philippine society. Its program, the Social Reform Agenda, addresses the issue of providing the marginalized sectors (which includes the Persons With Disabilities Sector) access to basic services by providing them with packages to enable them to meet their minimum basic needs and to live dignified lives. Through the SRA, KAMPI has initiated activities to organize PWDs all over the country. Meanwhile, government agencies have been tasked by the national government to coordinate with each other to find ways to better serve these marginalized sectors of society. Various forms of assistance, programs, and services, are currently being planned to support these sectors.

#### KAMPI's Seven Major Elements of Effective Community Organizing Endeavors

- Focus on the rural and poor disabled: This is a must element. About 80% of disabled persons in the Philippines belong to the marginalized sector. KAMPI focuses its attention to their alleviation from poverty by assisting them through training and provision of livelihood assistance for organized groups.
- Organizing small and informal groups of disabled persons in rural areas: KAMPI, through its member-chapters in the countryside, organizes small or informal groups of disabled persons. KAMPI believes that organizing small or informal groups legitimizes issues and concerns, thus, making it easier to bring up these issues and concerns to the national government for a response or action.
- Self-Organization and Self-Reliance: This is essential to





eventual sustainability. Thus KAMPI undertakes prior planning and activities to cushion the impact of phasing out by provision of skills development seminars, leadership training, etc.

- Generation of Livelihood Projects/Income-Generating Activities: This creates economic benefits which will facilitate self-reliance and long term viability. KAMPI encourages group savings and productive investment.

- Involvement of NGOs and key government agencies: KAMPI encourages multi-participatory involvement of these agencies and organizations to help strengthen grassroots development projects.

- Participatory Methods: KAMPI encourages participatory methods in decision-making and developmental processes. This element promotes empowerment and self-sustainability.

- Replicability: Promotion of similar projects in other communities is encouraged in order to reach out to provide benefits to the most number of people possible.

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## United Nations Conventions: Practical Applications

Anneli Joneken from Sweden is the chair of the Women's Committee of Disabled People's International.

The Human Rights of disabled women and girls have been ensured in many international documents such as the United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the universal declaration on Human Rights, the Convention on the Rights of the Child, the Covenant on Economic, Social and Cultural Rights and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The CEDAW-convention committee has adopted a General Recommendation (No 18/1991) which recommends the countries to report specifically on the situation of disabled women in their periodic country reports. Countries also report on specific articles regarding disabled children in the Children's convention, and a special recommendation regarding disabled persons attached to the Covenant on Economic, Social and Cultural Rights. All these documents I have mentioned should be seen as tools for improved lives.

Various important policy - and legal - documents, such as the Nairobi Forward Looking Strategies for Women from 1985 and the Beijing Declaration and the Platform for Action from 1995, also give valuable promises to ensure the Human rights of disabled women and girls.

In many countries, however, the authorities who are responsible to implement the human rights instruments are not aware of the situation and living conditions of disabled women and girls and the violations against their rights that occur in their countries. The women and girls themselves are not well enough aware of their rights and possibilities, and of how to get access to their own empowerment.



The society at large is not well enough aware of the lives of women and girls with disabilities, in order to assist in empowering them with possibilities and improvement.

#### CEDAW

In the CEDAW convention from 1979 discrimination in all forms is condemned. A committee of 23 experts is in charge of the reporting procedure and monitoring. The 30 articles of the Convention cover areas such as public and political life, education, employment, health care, economic and social life, rural women, equality with men before the law, matters relating to marriage and family affairs. For a couple of years an optional protocol has been in process to improve the strength of the Convention, which by many is felt to provide inadequate and insufficient means of implementation. The optional protocol would facilitate the implementation and give two new methods to the committee: a communications procedure and inquires. Individuals, groups and organizations would be able to submit communications. I think it would be very good if this Optional protocol could help raise more awareness around the CEDAW convention, and provide better ways to use it.

But even without the Optional protocol there is a good possibility for us to get included with our concerns into the reporting system of the CEDAW-committee. As mentioned, they adopted a recommendation in 1991, requesting countries to report on the situation of women with disabilities in their periodic reports. What we need to do is to find out when our own countries are processing their report and provide the government our expert opinions on the situation of disabled women in our countries. We might need to carry out surveys and arrange seminars. We would need to establish a continuing dialogue with the government entity which is processing the reports. And certainly, we need to work inter-nationally to get important information on these issues too.

#### Violence

A human rights instrument closely linked to the UN Human Rights center and to the Cedaw Convention is the Declaration on Violence Against Women. There is a Special Rapporteur and I think it would be very valuable if she could make a special survey on violence against women and girls with disabilities. In many countries, according to my knowledge, violence, sexual abuse and safety-issues are among the top priority issues and still very much tabu and causing pain.

#### Convenant

One of the special Human rights covenants adding to the Universal declaration of human rights is called Covenant on Economic, Social and Cultural Rights. A couple of years ago a general comment was adopted regarding persons with disabilities, regarding the articles of the covenant from the perspective of a disabled person. The articles cover: equal rights for men and women, rights relating to work, social security, protection of the family, of mothers and children, right to adequate standard of living, right to physical and mental health, right to education, to take part in cultural life, and enjoy benefits of scientific process.

This covenant is a good tool, but it is not so well known. Maybe we all as Human Rights activists could lift it up together with the other instruments in this field.



## Children

The Convention on the Rights of the Child from 1989 is a very important one for us to use and our societies to implement. According to Article 2, states shall respect and ensure the rights of each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parents or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status. In addition to this general statement at the beginning of the convention articles, Article number 23 in four paragraphs recognizes the right of every disabled child to enjoy full life in conditions which promote self reliance and facilitate the child's active participation in society, the child's right to special care, effective access to education, training, health care services and rehabilitation.

## Standard Rules

The next important tool I would like to mention is the Standard Rules on the Equalization of Opportunities for persons with disabilities, adopted by the UN General assembly in 1993. There are 22 rules in the basic fields of life, with some 10 additional rules attached to each one of them.

When you read the document you will find the mentioning of the gender dimension only in very few places. However, at the very beginning in paragraph 15, where the aim of the document is described, the text is the following: "The purpose of the rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others." It is when we use the document in our advocacy work that we can point out the gender aspect. In the text there are normally the words disabled persons, persons with disabilities, or children with disabilities. It is only by stressing the gender dimension that we can make the concerns of a disabled child visible, for example as regards her possibilities to get education, training or a job. Or the concerns of a woman with disabilities as regards sexual abuse and violence. Or her possibilities to become a mother. I want to stress the need to use the standard rules text in a gender specific way when appropriate.

The standard rules instrument should by all of us be thoroughly examined and the 22 rules should receive a special additional manual, where aspects of life of women and girls with disabilities are focused on in a structured way.

I really feel we need a better tool from the gender point of view of the standard rules. And also I would like us not to forget that we need to develop the Standard Rules into a proper convention later on with a better legal status.

In addition to these conventions there are other important ones in the domains of the specialized agencies such as the ILO, UNESCO, FAO (Food and Agriculture Organization) to mention just a few.

With several of the Human Rights conventions there is a severe problem, however, in the reservations many countries have listed in connection with their ratification of the conventions. We should take part in the lobbying for lifting out of the reservations by those countries. And we should welcome the ratification of the CEDAW-convention by the USA, as expressed earlier today.

## Developing our Priorities

Now I would like to mention a very special Experts seminar in Vienna in 1990. It was about disabled women, arranged by the





UN with the assistance from Disabled People's International. At this seminar Judy Heumann presented a very good back-ground document, and the participants developed some 90 recommendations very much in the same subject areas that are covered in the various conventions I have talked about. The recommendations cover education, leadership development, legislation, health, rehabilitation, transportation, massmedia, housing, to mention some.

In Europe, a working group recently has developed a continuation to the Vienna recommendations. It is called Manifesto by Disabled Women in Europe. There are 18 various chapters listing recommendations in priority concerns for disabled women.

1. Human Rights; Ethics;
2. National and European legislation; and other international legal instruments;
3. Conventions
4. Education;
5. Employment; Vocational training;
6. Marriage;
7. Violence, sexual abuse and safety;
8. Empowerment; Leadership development;
9. Disabled women with different cultural backgrounds;
10. Awareness raising; Mass media; Communication and information;
11. Independent living; Personal assistants; Technical needs and assistance; Counselling;
12. Social security; Health and medical care; Rehabilitation;
13. Public buildings; Housing; Transportation; Environment;
14. Culture; Recreation; Sports;
15. National focal point on women with disabilities;
16. International focal points;
17. Regional and sub-regional activities; Project funding;
18. Statistical information; Research

When we were writing the text we also tried to integrate a reference to respective Standard Rules, when applicable.

Maybe here at the Forum we could look at the European manifesto and develop it further to suit a global context. Or maybe develop new regional and subregional manifestos as practical tools for us in our advocacy work. Or maybe national manifestos.

The various conventions in the human rights area from the UN system provide good tools but they are not well enough known in our countries. I think we should jointly try to identify better ways to raise awareness around all these important documents, in the process of promoting the human rights of women and girls with disabilities.

In this awareness work we need partners. I would like to recommend to link to the UN Association in your country, the Unifem association, and the Unicef and Unesco-committees if there are such association in your countries. My experience is that these organizations consist of individuals and associations who at the national level could be effective partners in promoting our rights.

Last comments I would like to make referring to the Beijing process as I call it.

The preparations for the UN Conference on Women in 1995 in Beijing provided a tremendous possibility for us in the disabled persons' and womens' movements to lift up our concerns and discuss and promote them in different mainstream fora. We succeeded rather well with the texts in the Beijing Platform for Action, which is a political, not legal, document for change.

We need to continue, however, to get our issues to the various agendas in our countries and internationally. What we need is to work better together too. We might want to establish an international alert-system of sisters with disabilities. Maybe we should call it Womens' International Linkage on Disability, WILD.

We need to act effectively and continuously within the disability movement and the women's movement as well as within the society at large.



8/19/98



## Women Wheelchair Builders

Jenny Kern represents Whirlwind Women, a division of Whirlwind Wheelchairs International, San Francisco, CA, USA.

Since 1980, wheelchair riders and inventors from the developing world and the U.S. have worked to design low-cost, lightweight wheelchairs appropriate for the rugged conditions of most of the world's towns and villages. Hidden in these small towns of the developing world are many of the 20 million disabled people who need wheelchairs but have little likelihood of getting even one in their lifetimes.

The Whirlwind wheelchair developed by many innovators worldwide is the latest, most rugged design promoted by the Whirlwind Network. The Whirlwind Wheelchairs International (formerly Wheeled Mobility Center) was formed by Ralf Hotchkiss and colleagues in 1989 to facilitate design and production of the Whirlwind wheelchairs by disabled people in small, low-tech shops worldwide. Currently, over 35 shops exist in 25 developing countries.

## Whirlwind Women

Women with and without disabilities from various countries have worked as designers, inventors, mechanics, trainers and testers of the Whirlwind since the Whirlwind Network began. In addition, workshops with women as managers have traditionally been highly successful. Despite their many contributions, however, women have not been well supported and have often been squeezed out of shops by the male mechanics.

Recognizing the need to promote women's wheelchair building talents and to tap more fully into their inventive abilities, three women affiliated with the network formed Whirlwind Women in 1995. In August, 1995 Whirlwind Women traveled to the Hairou NGO Forum to meet activist women with disabilities interested in Whirlwind production and design. Gathering momentum from this historic meeting, Whirlwind Women planned a women's pre-training component to the next Whirlwind technical training held in Kenya in January, 1997. The intensive one-week course was designed to teach women basic tool use enabling them to make Whirlwind wheelchairs during the remaining three weeks of the training. The pre-training was highly successful with a group of disabled women from Kenya and Uganda participating. Most had not worked with metal in a workshop setting, although each had experience with other crafts. By the week's end the women had built most of the side-frame of a chair and had been introduced to welding, grinding, drilling and other related skills. The challenge for participating Whirlwind Women and all of us remains how to translate new skills and ideas into wheelchair production. We have as many questions as answers and currently, little funding. We attended the Leadership Forum to seek ideas from women leaders with disabilities who can work with us to explore future training opportunities in developing countries, business development of Whirlwind workshops, and other ways to promote our common goals.

## New Video

A 10 minute video documenting the Africa training, "Whirlwind Women: Building Wheelchairs" is now available in the NTSC and PAL formats at a special rate for non-profit groups of



\$30 including airmail postage from Whirlwind Wheelchairs International, San Francisco State University, School of Engineering, 1600 Holloway Ave., San Francisco, CA 94132, USA. A 60 minute version is in development and details are available from Jenny Kern, tel. 1 510 644 1205 or e-mail: JKernesq@aol.com.

## Conclusions

**\*\*People need wheelchairs-**approximately 20 million people in developing countries need wheelchairs and are unlikely to get even one in this lifetime. Women with disabilities are badly needed to bridge this enormous gap.

**\*\*Women with disabilities need jobs-**women with disabilities worldwide remain unemployed at staggering rates, despite their many abilities and untapped potential.

**\*\*Women can build wheelchairs-** Whirlwind history proves it. The Kenya training showed us the way forward.

**\*\*Whirlwind Women needs to work with emerging and established groups of disabled women to promote women wheelchair builders worldwide.** We know no one can do it for us. An international movement for human rights of disabled people with women in the forefront can begin to work toward vital change.

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#### The ILO Experience with Employment Strategies and Women with Disabilities

Evy Messell of Norway, is the Senior Specialist on Disadvantaged Youth and Women, Vocational Rehabilitation Branch, International Labour Organization, Geneva.

Today, on our fifth day together, we will be dealing with the issues of how to ensure women with disabilities have better access to the labor market, be it in the open labor market or through protected employment schemes for persons with disabilities and that these jobs are relevant to their education and aspirations.

I will first present some key issues related to the difficulties many girls and women with disabilities face in obtaining jobs which suit their acquired skills, and to touch upon what official policies and structures need to be in place to promote employment of women with disabilities. The points I will mention are based on ILO's experience in working with employment questions at both the macro level and directly with women with disabilities, in their efforts to be heard, respected and accepted as productive workers in the world.

Many of the problems linked to ensuring that women with disabilities have access to productive and freely chosen employment are often the same for women coming from countries with different cultural, social and economic backgrounds.

#### Education

Nowhere can one talk about employability of women with disabilities without making reference to their access to education as girls. In most countries in the world, if not all, the effects of the disability have made it much more difficult for them to reach the educational level required for the occupations they aspire to. In some cultures, girls and to an even greater extent girls with disabilities, face discrimination within the family and the community because of their gender. Some social environments assume that women who are disabled should not



even work, and that their financial security should be provided by their families and that their main role is to be at home. In contrast to this, other countries effectively and successfully integrate girls, boys and adolescents in the school system and bring forth generations of disabled young women with high expectations of comparable integration at the workplace. But even in these societies it has proved difficult to adapt the situation, because low priority has been given to disabled persons in the labor market policies, and therefore it is particularly difficult for young educated women with disabilities to get a job. In Sweden, for example, out of the 30,000 employed (1996) in the large government subsidized sheltered corporation Samhall, 42% were women as compared to 58% men. After many years of ignoring this fact the management now finally plans to launch a research project on why fewer women apply for jobs and why they are hardly ever found in management positions. The ILO survey on women with disabilities in six Asian and Pacific countries showed that women with disabilities who had completed secondary school, had diplomas in a vocational skill or had a university degree still encountered problems in being hired. This, without a doubt, shows that there is a significant differential in the employment status among young women with disabilities when compared to the total female labor force in these countries.

We also know that many women are responsible for the financial security of their families: global statistics show that one third of all families are supported by women in absence of men for various reasons. Many disabled women belong to this group, as they may have family responsibilities, or because disability strikes them later in life while they are fulfilling those commitments.

We can conclude that to get access to training, one needs a basic education, and to get an education one depends on a supportive environment within the family structure and the local community, and also a national policy that supports it. The education and vocational training policies should ensure that girls and young women with disabilities have access to the mainstream programs and when necessary are provided with the supported special training.

## Employment

Very little data exists at the macro level on women with disabilities and employment. The general trend in most countries is that there is higher unemployment among women than men with disabilities. Most women with disabilities therefore have no regular source of income.

In Ghana, for example, disabled women do not count for more than 3% of the female labor force (1996). One reason given is that women with disabilities do not have easy access to credit.

Although the 1992 Constitution of Ghana guarantees the rights of minority groups for credit schemes within the program "Enhancing Opportunity for Women in Development", it was silent about women with disabilities when it was implemented a year later.

In India it was estimated in 1991 that out of the 22.27% work participation rate of women workers in the formal labor force, only 0.3% were women with disabilities, and amongst those who worked, they got lower wages and worked longer hours.

A survey of women with disabilities in the Philippines revealed that only 19 % of disabled women were employed. Furthermore, 95% of those who were employed had to settle for very low wages, earning about one-third of the poverty threshold set by the World Bank for workers in rural areas.

In some industrialized countries, the financial and social implications for joining the labor force is so complicated and unfavorable for the persons with disabilities, that many women choose in the end not to seek employment, since the working



conditions are such that they are better off receiving a disability pension.

In Sweden 59% of women with disabilities had jobs in 1995 as compared with 66% of men in the age group 16-64 years. Even if the women were better educated, the men received more pay and a higher percentage from the state-subsidized salary support program for persons with disabilities. This being said, among the many working women one finds some in well placed decision-making positions.

A relatively large number of women with disabilities in industrialized countries work part time. But the question to raise is: do the women choose to work part-time or are they forced to do so since they do not get the necessary assistance at home to allow them to work full time? Indeed, at first glance it would seem that part-time work might be ideal for women with different types of disabilities. Competition however, is often intense for part-time jobs, and women with disabilities are often not considered, since employers assume they often are ill, absent or unable to stand the pace.

### Self-Employment

In contrast to this situation the majority of women with disabilities living in developing countries where no government financial support systems exist, and most of the working women are found in the informal sector, the issue of working part-time cannot even be considered as an option. For example, in Pakistan, Thailand and Fiji most of the working women interviewed for an ILO study on women and disabilities confirmed that they were self-employed. The same goes for a number of countries in Africa and Latin America.

Growing numbers of women, both able-bodied and with disabilities are found in the informal employment and self-employment areas, often in line with traditions in the country they live, but also owing to the lack of other opportunities. Their training needs should not be ignored and special efforts should be made to attract disabled women in the informal sector to enter such training schemes. Such training should involve women-oriented NGOs, community-based institutions and grassroot womens' organizations to enhance the effectiveness of the programs.

### Strengthen NGOs

Nuggehalli Sitaram Hema writes that " the NGOs , working in rural and semi-rural areas and urban communities, have brought about drastic changes in the lives of large numbers of women. It is through their efforts that the women, with or without a disability in these communities are being seen as target groups for educational and training programs. Governments often endorse these programs". This is true in a number of countries, and therefore it is imperative to strengthen NGO capacities to implement training and income generating programs for women with disabilities. But I would argue that parallel with promoting employment opportunities for women with disabilities at the local community level, we need to look at how, at the macro level, national policies and planners provide or do not provide opportunities for women with disabilities as compared to the rest of the population.

### Labor Market Policies

Labor market policies should ensure access to both mainstream and special education and training at all levels to enable women with disabilities to participate in programs which would help them



obtain and retain employment, and, in accordance with the basic rights and protection of women with disabilities by implementing the Beijing Platform for Action. The policies should also deal with the situations where the employer needs to adjust the access to the workplace or modifications at the workstation. The policies should moreover open up different employment options for women with disabilities, including supported employment, sheltered workshops, part-time work, flexibility in working time arrangements, public sector employment, self-employment and entrepreneurship development with access to credit schemes.

### International Policies

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities stresses the aspect of having access to employment as a human right. All the points listed are, however, gender neutral, it being explained in a hidden paragraph at the beginning of the document that "the purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights as others." I personally believe that the document, and in particular Rule 7, on employment, would gain from being more gender-specific in its recommendations, since we know that in many working environments men with disabilities are favored. In order to meet the pre-requisites for a successful employment strategy for women with disabilities the policy statement should include standards which guarantee that measures are enacted that promote equitable vocational, pre-employment and on-the job training in all sectors of the economy. These points are clearly stated in the Beijing Platform for Action. The ILO Convention No.159 concerning the Vocational Rehabilitation and Employment of Disabled Persons has so far been ratified by 58 countries and is also an instrument that one can use to remove the barriers and to promote economic self-reliance.

### Mainstreaming

Mainstreaming is understood in this paper as being: the integration of the concern of women with disabilities into all aspects of development planning by explicitly considering the actual and potential role of women with disabilities in all sectors of the economy. Hence, there is a need to mainstream initiatives by and with women with disabilities within able-bodied women's advocacy work. Networking between the women leaders in different kinds of women organizations and NGOs for women with disabilities is imperative if we want to succeed and be heard when we promote: empowerment issues, training needs, the follow up of the Beijing Platform of Action, employment opportunities etc..

I have noticed over the many years that I have worked with women in development- and gender issues, that we are often talking about two very separate worlds, when promoting the overall human rights for women with disabilities and non-disabled women. When I collaborate with women NGOs, women information/research centers, women trade union leaders or female employers, I have come to realize that there is very little knowledge and awareness among these women on what are the special considerations to be included in promoting employment opportunities for women with disabilities. In most cases these womens' networks do not include NGOs of women with disabilities. I believe this to be an unintended exclusion. Likewise, when working with groups and organizations specifically targeting women with disabilities, I realize that they often miss out on the networking and joint programs with the other women movements. Having said that, it is all the more gratifying to see what a fantastic job the women with disabilities did in Beijing,





in terms of including disability issues into all the sections, including the one on employment. Mainstreaming is also important to apply in the case where the social environment demands women in general to respect men as leaders, which for women with disabilities means that men are in charge of organizations of disabled persons and do not easily recognize that women face discrimination because of their gender. This can result in women receiving less training, fewer job opportunities and receiving lower wages. The women should aim at finding their place in the management of these organizations, rather than accepting that their place is only in the "womens' wing".

Let me conclude with a words of thanks to the Forum organizers by saying that the ILO is proud to have been invited to participate in this unique conference which demonstrates how powerful women leaders with disabilities are and that no mountain called discrimination is too high to scale, if the accessibility to the tools is provided!

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## Building Leadership Among Disabled Women in Southern Africa

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### Formation and Objectives

The Southern Africa Federation of the Disabled (SAFOD) was formed in 1986 to promote the formation of organizations of disabled people and to strengthen existing ones. When it was formed there were only a couple of organizations in Zimbabwe and Zambia which were controlled by disabled persons.



The role of SAFOD is to mobilize disabled people in all the countries in Southern Africa (ten countries in all) to form organizations of their own and bring together all disabled groups into one umbrella organization.

Identifying and mobilizing the disabled people to come together into groups and organizations was not an easy task for obvious reasons. In all countries in Southern Africa disabled people were isolated from each other, segregated by inaccessible buildings, locked up in institutions or rehabilitation farms and hidden away by families who were ashamed and frightened of them. Meetings were organized in the villages and in the urban centers which enabled different disability groups to come together to share their experiences and problems and generally to talk about their lives. They realized that they were not alone, they began to support one another and to see the need for forming their own organizations.

The period 1986-1992 saw many organizations emerging in all the countries in the region. Through these organizations, many disabled people began to realize that their problems were not a result of their individual disabilities but because of fear and superstition about disability by non-disabled people and the fact that society itself does not consider the existence and needs of disabled people in its organization.

Through these organizations people with disabilities in the region were provided with a voice of their own. Having the same needs and rights as non disabled people, people with disabilities identified the following as being essential for their development:

- social life
- food and money
- dignity and respect
- access to community services
- access to specialist services
- forming relations
- sexuality
- having a family

Indeed each organization in the region is unique in terms of structure, membership composition and size and program implementation; but they all have a common philosophy and/or ideology which is founded on the commonality and source of their problems.

The philosophy of all these organizations is about overcoming discrimination against people with disabilities, it is about enabling them to regain choice, rights, dignity and control; it is about self-organization and self-determination and self-representation.

In Southern Africa we now have the following national umbrella organizations that are members of the movement of disabled people in the region:

- National Association of Disabled People in Angola (ANDA)
- Botswana Society of People with Disabilities (BOSPED)
- Lesotho National Federation of the Disabled (LNFOD)
- Disabled People's Association in Malawi (DIPAM)
- Association of the Disabled in Mozambique (ADEMO)
- National Organization of the Disabled in Namibia (NODPN)
- Disabled People South Africa (DPSA)
- Federation of the Disabled in Swaziland (FODSWA)
- Zambia Federation of the Disabled (ZAFOD)
- The Zimbabwe Federation of the Disabled (ZIFOD)



## Programs

Needs were identified through these national organizations and their grassroots members, and in response to these needs SAFOD came up with a number of development programs some of which are as follows:

? Leadership Development program for creating a pool of leaders with ability to articulate the needs of their members and to concretely contribute to the processes of effecting change in their daily lives;

? Awareness-building and Public Education Program for attacking the causative factors which lead to the underdevelopment of people with disabilities;

? Equalization of Opportunities Legislation Program which is influencing Legislation to provide equal opportunities to persons with disabilities;

? Small Scale Enterprises for Economic Development whose main objective is to assist grassroots members to engage in self-help projects by giving them loans and appropriate training in business management;

? Training and Exchange Program for organizing training seminars for development workers and other personnel of disability organizations; and for organizing inter-organizational exchange visits and tours;

? Women's Regional Development Program, which was basically designed and is working to:

- a) develop leadership skills among women with disabilities,
- b) encourage women to form their own women's action groups (WAGs) at national and local level,
- c) facilitate exchange visits and information exchange between women's action groups,
- d) provide financial support to self-help projects for women with disabilities at national and local levels;
- e) organize seminars, workshops and conferences for women with disabilities.

## Women's Issues

The Women's Program was launched in 1989, three years after the founding of SAFOD. Following the first women's regional development seminar of July 1989, the program engaged in many awareness raising activities which have helped raise the profile of women in Southern Africa and in the disability organizations themselves.

The launching of the Women's Program was necessitated by the following issues that were and are still great concern to women with disabilities.

? disabled women lacked opportunities for education and/or training for self-improvement and independence, thus destroying their self-image and self-esteem, creating inferiority complex and severe frustration;

? disabled women were often isolated and confined to the house, the situation being worsened by socio-cultural patterns and traditions which surpass legislation;

? marriage is a much greater problem for women with disabilities than for men due to cultural beliefs;





? if a disabled woman is married and has children, she is not considered fit to look after them which naturally deprives her of a role important for her emotional and personal dignity;

? the attitudinal barriers practiced by the health professionals tended to reflect the attitudes of the society in general, that people with disabilities are non-sexual, and as such do not need to learn about birth control - disabled women are also regarded as incapable of childbearing or raising families;

? institutions, where these exist, have fostered dependency and vulnerability of disabled women to be sexually abused by attendants in institutions.

### Leadership

Structurally, the Women's Program is managed by a Women's Coordinator who is one of the senior members of staff at SAFOD Headquarters in Bulawayo, Zimbabwe, and is supervised by a policy formulation body called SAFOD Regional Women's Committee (SRWC) which consists of a woman representative from each of the SAFOD member countries. Each representative on the SRWC is tasked to ensure that at national level women are brought together to voice their concerns and issues. The representatives meet from time to time in each year to draw up plans for implementation, and every two years they meet to review progress of the program and to elect an executive committee for SRWC.

The main SAFOD Regional Executive Committee is made up of 50% women and 50% of men, with two deputy chairpersons, one of whom is a woman responsible for women's affairs. The executives committee is elected from among twenty delegates (two delegates from each country, a man and a woman) at a general assembly held every two years. In fact, SAFOD's constitution provides for equal participation of men and women in all its activities and structures. This constitutional provision was demanded by women five years ago when they called for:

? all national delegates to the SAFOD general assembly to consist of at least 50% women;

? the post of chairperson or deputy chairperson or both to be held by a woman.

? the women's committee to monitor progress in SAFOD and other mainstream organizational structures to ensure and/or enforce appropriate representation by women with disabilities.

### Evaluation

In 1995 the entire organization was evaluated and it was noted by the evaluators that the biggest stride SAFOD had made was on the Women's Developmental Program. The evaluators noted that the Women's Regional Developmental Program had done well on the public awareness front as most SAFOD countries now have women's action groups (WAGs) in place. The constitutional claim by disabled women to 50% in all decision-making bodies and in all program activities is an achievement which is more than can be said for many organizations run by the non-disabled women in Southern-Africa or anywhere else in the world. The credit must go to the women leaders themselves who, apparently have benefited from the large movement of women's liberation globally within the region.

The evaluation report further observes that the disability movement in Southern Africa is now "out of the closet" - it is



on the streets, in parliaments, in non-governmental organization, in inter-governmental organizations, it is open. It is part of the larger "human rights movement". The "charity" or welfare model no longer reigns supreme, nor does the medical model.

From what I have so far presented it would appear that a lot has been achieved by SAFOD and its member organizations in Southern Africa. In my view, I think we have only managed to "scratch the surface" in terms of helping society to transform itself into a new society where disabled people are treated with dignity, respect and on the basis of equality. A lot more still remains to be done. Disabled people in the region continue to experience hardships as a result of negative attitudes and ignorance on the part of society. Indeed, it takes many years if not centuries to change deeply-rooted attitudes, and the work of SAFOD and its affiliates is about changing attitudes and coordinating development work of its members.

The Second Regional Development Plan (1995-2000) will enable the organization to address itself to the other important issues that have been identified by the movement, and also to address itself to the other important issues that have been identified by the movement, and also to address itself to the recommendations of the 1995 evaluation.

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Promoting the Rights of Women with Disabilities:  
Progress Report on South Africa

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Introduction

The term "women with disabilities" is utilized broadly in this paper to include race, class, ethnicity, sexual orientation and culture. It also recognizes that disability is a socially constructed concept and therefore a shifting concept. It means different things to different people with different disabilities.

This paper presents an overview of policies, law reform and programs that impact on the status of women with disabilities in the new South African dispensation. The second part of the paper describes the national machinery that promotes the rights of women with disabilities. Finally, I examine, more specifically, basic human rights of women with disabilities enshrined in the Bill of Rights of the South Africa Constitution(1). A Constitution that has at its core principles equality, non-racism and human dignity(2).

Background

When we chart the progress and change in South Africa we need to recognize the context in which democracy arrived. In April 1994, the new Government inherited a State that was geared towards serving a minority at the cost of oppressing a majority. Therefore, today the Government's major challenge is to transform the State, to meet the needs of all the people. One needs to note that this process of progressive transformation has and will continue to be met by elements of resistance.

Considering the magnitude of need in the country post 1994, the Government of National Unity has been diligent in contemplating the achievement of equality. Many of these



initiatives are policies and statutory provisions. The Constitution is the supreme law of the land and guarantees, in the Bill of Rights, the attainment of basic human rights. There is a new found body of national legislation that gives substance to these rights. It includes inter alia, the South African Schools Act (No 84 of 1996) and the Labor Relations Act.

#### Situation of Women

South African women are not a homogeneous group. The population of women in South Africa is approximately 20 million(3). A large percent of South African women live in the remote areas. A recent survey shows that women in rural areas are possibly more likely to have a disability of some kind than rural men, but not more likely than urban women (4).

Self-representation is a crucial issue in any democracy. Thus, a decision by the majority party, the African National Congress (ANC), to have a 33.3% women "quota" in Parliament has had significant impact. The increasing number of women MPs and Ministers is a sign of emerging empowerment and emancipation of South African women. Women with disabilities are no exception but there is room for growth.

Like women globally, patriarchy continues to subvert the full emancipation of women in South Africa. Positions of power and decision making still remain largely within the domain of white men with disabilities.

Women with disabilities are not a monolithic group. They share however many common experiences. Women with disabilities as a collective are still excluded from civil society in a variety of ways: to a large extent women with disabilities are still considered as asexual, incapable of being good parents, unemployable and unable to take measures of responsibility regarding their lives and bodies and not worthy of full citizenry.

Paradoxically, this population has made a significant contribution in the political growth of this country. Many women became disabled during the struggle for freedom. With the attainment of equality as their mantra, women with disabilities continue to contribute to the growth and development of the new South Africa. In the current political arena we have women with disabilities in the National Parliament, as representatives to the Gender Equity Commission and maybe more importantly as a voice, a collective voice dedicated to realizing the rights enshrined in the Bill of Rights.

The reality remains that women with disabilities still remain among the poorest of the poor. The backlog of little or no education, limited access to information and meager resources significantly contributes to a cycle of poverty and disability. It must be noted that complex debates around transformation, growth and economics often overshadow the attainment of basic needs of the most vulnerable. It must also be said, that sustainable transformation and development should see the alleviation of poverty and integrating disability issues as part of a determining a human rights culture for all of society.

#### International Legal Instruments

On December 15, 1995, the Government of National Unity ratified the United Nations Convention on the Elimination of all forms of Discrimination Against Women (hereinafter CEDAW). This CEDAW sets standards of what must be done to achieve equality. Consequently, a parliamentary committee has been established to monitor the implementation of CEDAW. CEDAW does not per se address specifically women with disabilities. It does however speak to generic issues related to women's equality which





clearly impact on the lives of women with disabilities.

The Government committed itself to the Beijing Platform of Action adopted at the 1995 United Nations Fourth World Conference on Women in Beijing. The Platform of Action does recognize rights of women with disabilities. Further, it is also quite apparent that post-apartheid legislation, as it relates to people with disabilities, is guided by the United National Standard Rules on the Equalization of Opportunities for Disabled Persons (1993). However notwithstanding this it has been recommended that government ratify the International Covenant on Economic, Social and Cultural Rights (1996), particularly in regard its provision on the right to work.

The National Machinery for the advancement of women is coordinated by the Office on the Status of Women, situated in the Office of the Deputy President, is responsible for ensuring that all government departments adhere and implement policy that are gender sensitive and promote equal participation.

The Commission on Gender Equality seeks to promote respect for gender equality and the protection, development and attainment of gender equality. The Commission has the power, as regulated by national legislation to monitor, investigate, research, educate, lobby, advise and report on issues concerning gender equality. (Women with disabilities are represented by Commissioner Beatrice Ncobo, a disabled woman present at this Forum)

The South African Human Rights Commission (5) is a permanent statutory body that was enacted by the Constitution to protect and promote human rights in South Africa. Among various sub committees a Disability Committee was established. It will be chaired by a Commissioner with disabilities.

The Office on the Status of Disabled Persons. This Office is similarly placed in the Office of the Deputy President, TM Mbeki. Early in 1996, this Office released a Green Paper on the Integrated National Disability Strategy(6). The core of this Strategy is to create a society for all. Importantly, the Strategy articulates the need to introduce a new paradigm shift that views disability not exclusively as a welfare issue or a health issue but rather as a human rights issue. Moreover, this Office is currently responsible for developing a White Paper - the Integrated National Disability Strategy. Notably, the process of developing this White Paper has been very participatory and transparent. The draft White Paper outlines the key policies which need to be developed by line function ministries. They include inter alia inclusive education for all, community development, self representation, public awareness and accessibility. The White Paper was expected to go to Cabinet in July 1997.

The Public Protector. Is the official watchdog against government's maladministration, unfairness and the mis-allocation of public funds. This statutory institute is very important for women with disabilities. As consumers of services women with disabilities are often confronted with service providers who are ignorant of the law, misconstrued the law or are basically hostile, leaving them with the burden of indirect or very often direct discrimination.

The Constitutional Court. Is the guardian of the Constitution. Its main function is to uphold the rights guaranteed in the Bill of Rights which are fundamental to a democracy and equalizing the rights of all South Africans. There has yet to be a disability specific discrimination case before the Court.

#### Provincial Structures

In many provincial departments Gender desks have been established. Women with disabilities must utilize these structures and make them work for them. Furthermore, at a provincial level negotiations are ensuing regarding establishing disability desks in Premier's Offices. Already, two out of the



nine Provinces have staffed these Offices.

## Health

The Department of Health has made some sterling inroads in realizing the constitutional right to basic health care particularly given the fact that health services and access to medicine have traditionally been a preserve of the privileged. The introduction of free primary health care for under six's and pregnant mothers has been highly applauded. Within this plan health care programs such as risk factors before birth or in childhood can be identified and preventive action taken (8). A policy by this Department of subsidizes assistant devices, at 60% . This policy has been employed in most of the provinces.

There are some outstanding issues that need to be addressed in this department. Of particular concern is the forcible sterilization of women with disabilities. The frequent reports of this nature have led to suggestions by human rights activists, that the Gender Equity Commission and/or the Human Rights Commission investigate this flagrant abuse of women's bodily integrity and a violation of their reproductive rights. Critical attention needs to be given to awareness education around reproductive rights for women with disabilities.

## Education

The South African Constitution articulates the right to education as a fundamental right in Section 29(9). The right to education is premised on the past imbalances and redress, hence the inclusion of Adult Basic Education. Furthermore, the Constitution provides for the right to be instructed in the a person's language of choice. (10) This provision allows for Sign language in schools.

The South African Schools Act, 1996 provides for compulsory school attendance from the age of 7-15. This includes, inter alia, children with disabilities. Some provincial Acts make provision for assistive devices for learners with special education needs (11).

## Budget Allocations

Last year a historical milestone was laid when the Women budget was moved at national Parliament. This budget is not a separate budget for women. It is a concept that monitors budgetary allocations at all three levels of government with the view to determining its impact on women.

Women with disabilities have been historically left out of mainstream planning which has been for so long been white, male, able-bodied, middle class dominated. However, the dominance of able-bodied people permeates into the mainstream women's movements. Women with disabilities have quite frankly been a silent other voice.

From all accounts, Beijing was interesting testimony to this. Women with disabilities were relegated to obscure venues suggesting otherness rather than diversity. However, this proved to be rewarding as women with disabilities forged out their commitment and contributed to a comprehensive document (the Beijing Declaration and Platform of Action) which makes considerable note of women with disabilities and their rights. In Beijing, women with disabilities clearly etched out their political space.

The lack of employment opportunities for women with disabilities often makes them financially dependent on their families throughout their entire lives or dependent on state welfare. Research shows that dependency of this nature corrodes peoples'



self respect and exacerbates social isolation. The new Labor Relations Act ushers in a new era of equality and opportunity in the arena of employment. The Act disallows any form of discrimination and makes provision for redress in the form of affirmative action programs. The Public Service Act puts in place a target that by the year 2000, 2% of the Public Servants will be people with disabilities. There clearly is a need for more formalized training programs for women with disabilities.

#### Research, Policy Development

Research is key if women with disabilities want to take control of their own lives. We need to know how to motivate budget allocations with facts and figures. We need to understand the strength in lobbying and use it. Research should not be esoteric but informed on what happened on the ground with the aim to effect change. "Desegregated data is needed to demystify the apparent neutrality and, more specifically, the gender neutrality of the budget." (12)

Learning from other countries is a rich resource. We would like to exchange and share through networks and Forums such as this our varied experiences. I believe that relevant research needs to be generated by women with disabilities to chart appropriate policy that guides us into the next millennium. Justice

Women with disabilities in the justice arena face the same obstacles most women face but have the added dimension of being disabled. The Minister of Justice recently announced after much pressure from women and children's lobby groups that "violent crimes against women and children will fall within the ambit of priority crimes." The call to prioritize these crimes was precipitated by an escalation of violent crimes against women and children.

Women with disabilities are seen as "soft targets" of crime and hence often victims of crime. Further, the dualism of being a woman and having a disability often lends itself to secondary victimization by and in the legal system.

#### Welfare

Historically, welfare services for people with disabilities tended to create dependence rather than sustainable development and self reliance. Today the Department of Welfare has adopted an inter-sectoral approach in its provision of services. Their proposed guidelines to meeting the needs of people with disabilities are generic and community based. The Department has also committed itself to public awareness campaigns about the need for improved public communication measures to facilitate the integration of people with particular disabilities (such as people who are deaf and blind) into all spheres of social life. (13) The departments policies recognize that "employment is the most important empowering tool to enable people with disabilities to become an integral part of society."

#### Programs at Community Level

Community expectations of government continue after the watershed elections of April 1994. Disabled People of South Africa, is the largest disabled people's organization in the country. It has with much foresight set up the Women Development Program. This organized effort is an illustration of women with disabilities carving out their political space and honing into the politics of the day. The objectives of this program is focused mainly on building capacity of women with disabilities as well as leadership skills.





Women with disabilities want equal opportunities and social development. However, to attain these objectives the following things needs to occur:

- equity of access to opportunities for all women with emphasis on women with disabilities regardless of their race, status, sexual orientation or religion.
- programs in communities that will facilitate self help and sustainable development
- leadership programs that emphasise the protection and development of the girl child with disabilities.
- involvement of disabled women in local government politics.

#### Communication and the Role of the Media

The recognition of Sign language in the Constitution as a language to be developed by the Pan South African Language Board is triumphant. Sign has also been recognized by the South African Schools Act, 1996. This victory needs to be linked to ongoing partnerships with the Deaf community and other role players.

The role of the media is central to changing attitudes of civil society. Communication strategies need to be developed by people with disabilities that project them as contributing citizens.

#### Conclusion

Quite proudly I can say as a South African, much is happening in regard to legislative reform and this is very important. However, legislation in and of itself cannot stand alone. It must be accompanied by progressive concepts of social justice and social development, diversity and tolerance that are packaged in the form of sustainable programs and appropriate training that empower women with disabilities to champion the many obstacles ahead. Fundamental transformation can only be achieved by strong, diversified and committed women movements that are visible at all levels.

Finally, I would like to share with you the words of the preamble of the Constitution which read: "let us stand united in our diversity."

#### References

- (1) Constitution of the Republic of South Africa Act 1008 of 1996. The new Constitution became sovereign law of the land on February 4, 1997 when it effectively replaced the interim Constitution of 1993. The only part of the 1993 Interim Constitution that still remains is the provision for a Government of National Unity
- (2) Ibid, Section 9 and section 10.
- (3) Status of South African Women. A sourcebook in tables and graphs. Published by the ANC Women's League Policy Division. 1993.
- (4) Statistics provided by Debbie Budlener Central Statistics Service June 1997.
- (5) The Human Rights Commission was established in 1995 in terms of the Human Rights Commission Act, No 54/1994 signed into law by the President on November 24, 1994. The Human Rights Commission consists of eleven (11) Commissioners elected by Parliament.
- (6) Integrated National Disability Strategy, No.17038. Notice 299 of 1996, Ministry in the Office of the President.
- (7) The National Youth Commission Act 19 of 1996. The Commission is constituted of five full-time members and nine Commissioners, nominated by Premiers of each Province and appointed at national level.





(8) Poverty and Disability. A position Paper by the Swedish International Development Authority. (SIDA) Health Division, Ingrid E. Cornell.

(9) Section 29 (1) reads as follows: "Everyone has the right - (a) to a basic education, including adult basic education; and (2) to further education, which is the state, through reasonable measures, must make progressively available and accessible.

(10) Section 29 (2)

(11) There are three provincial Acts in place. The Western Cape Act makes specific provision for assistive devices for learners.

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### Situation of Women with Disabilities in Asia

Yukiko Oka Nakanishi is the President of the Asia Disability Institute and Chairperson, DPI-Japan International Committee

A popular Japanese expression says that "A woman has no house to rest in anytime", meaning that a woman should obey her father as a child, her husband as a wife, and her children as an elderly person. In Japan, as elsewhere in Asia, women continue to be treated as substantially inferior to men. The problems of women with disabilities are more intensive than those of women without disabilities. The issues and problems facing women with disabilities are numerous as all of you are already aware. Poverty and injustice are at the core of the vulnerability and deprivation of women with disabilities. Development assistance which is provided by their colleagues, other women with disabilities, is done to help them get access to resources and acquire power over resources. This presentation will focus on development assistance models and philosophies for women with disabilities who struggle to achieve independence in Asia, first from the viewpoint of a development program organizer and then from the viewpoint of a witness of empowered self-help movements.

### Concerns to Be Noted for Development Assistance Program

The gap between rich and poor people, and rich and poor nations, is widening in the world today. Women and girls are among the poorest. The survival of those with disabilities is especially threatened by poverty. Their poverty seriously reduces their health and well-being. This makes their participation in the development of their community and their society almost impossible.

Socioeconomic status is directly related to the quality of life. Low social status, poor health conditions and limited ability to access economic and political resources go hand in hand.

The traditional model for service delivery is vertical, based on technology provided by professionals and institutions. It is expensive and available predominantly in urban areas. It is difficult for women with disabilities to use the services due to lack of information; hesitation to ask for services; lack of independent mobility; and lack of money for transport and fees. They sometimes are very much afraid that their request will be rejected by professionals, even if they can reach the service provider.



Community-based rehabilitation (CBR) is one of the examples of an alternative horizontal approach. Since CBR encourages women with disabilities towards community participation as CBR workers and service users, it is an effective way to give women access to decision making and benefits. In terms of human rights of women with disabilities, it is better for, but hardly gives the full guarantee of, their independent living in the community, especially when they need to be integrated into social life through marriage and child bearing.

It is easier for women with disabilities to claim their right to access to projects, if they are backed up by special supportive measures.

#### Related Attention of Funding Organizations

The need for integrating women in the development program has been emphasized for the last two decades. It was placed on the agenda of the International Women's Year. To translate it into action, such organizations in the United Nations as the International Research and Training Institute for the Advancement of Women (INSTRAW) and the Voluntary Fund for the Decade for Women, which was later renamed as the United Nations Development Fund for Women (UNIFEM), were created in 1975 and in 1976 respectively. The purpose of these organizations are to provide direct technical and financial support to development projects for women as well as to promote the inclusion of women.

In the field of international development cooperation for women in general, a welfare approach was applied in the 1950s and 1960s. This meant that women were viewed as purely passive beneficiaries in the development process and only to emphasize their reproductive role. The same approach is still taken toward women with disabilities in the present world.

The above UN organizations have contributed a lot to aid and advocacy for disadvantaged women of the developing world through the provision of assistance to trade and industry, credit, science and technology, agriculture and food security, and policy-making and national planning concerning targeted groups of women in respective countries. Evaluations have been conducted on their services, and there are reports that they have succeeded in including gender in international and national policies for refugees and displaced persons, violence against women, human rights, and environment. However, women with disabilities are not their priority area nor target group for whom an assistance project is implemented.

The reasons for lack of more substantial social progress for women with disabilities over the past two decades are many. In fact, development efforts ignore their needs, and continue to be directed at improving the social and economic conditions of women at large in developing countries. Their capability as a co-partner in development is underestimated by the international development community, which results in the maintenance of the status quo: social and economic marginalization of women with disabilities.

This is true of many other international organizations. The World Bank, for example, stated in the 1966 annual report that poverty reduction and sustainable development remain the central objectives. Yet no concrete program for women with disabilities is put on their discussion table. NGOs are known to be more flexible and more committed towards disadvantaged people than governmental institutions. But at the same time, NGOs have conceptual and institutional weaknesses connected with the role assigned to them. Women with disabilities are neither recipients of services nor partners of development.

#### Activities of the Asia Disability Institute

Since women with disabilities are able to contribute to the



local community and national development and, the Asia Disability Institute (ADI), as a consumer organization, implements projects applying the self-help approach. It was established in 1990 to promote independence of persons with disabilities in Asia. There are various assistance projects implemented by international NGOs. But the majority of them aim to strengthen the present rehabilitation scheme through the construction of centers or training of professionals. This tendency is particularly strong in Asia.

ADI aims through the Asia-Pacific network of Disabled Peoples' Intentional are:

- increased understanding of the concept of independent living and development of the independent living movement;
- physical and technical assistance to self-help groups of persons with disabilities;
- support to international exchange programs among persons with disabilities; and
- information dissemination and social education on disability concerns in Asia.

The priority area of the ADI's activities is the organization of various independent living study projects jointly with other self-help organizations of persons with disabilities, for leaders with disabilities in DPI member countries such as Thailand, Philippines and Bangladesh. The local co-organizer often does not have experience to organize such an international program. ADI, therefore, takes responsibilities of all phases of implementation ranging from preparing invitation letters, screening the applicants, to coordinating the study project and conducting evaluation. The ADI's input has helped to promote awareness concerning gender sensitivity among those who are involved in the projects.

#### Annual Independent Living Study Program in Japan

The Independent Living Study Program in Japan has been organized annually since 1992 for DPI members in the Philippines and Thailand. The 4 to 5 participants receive training at independent living centers and other related facilities including a day activity center and sheltered workshop in several cities in Japan. During the Program, they stay at a disabled person's house, which makes it easier for them to understand that the Japanese well-built accessible environment and well-established service scheme is not good enough to exert their full right. By the end of the program, all of them realize that their self-help group should be strengthened to attain independent living.

One of the conditions to participate is that the counterpart in each country is to pay attention to the balance of gender of the nominees. We have received 21 trainees, among whom 9 are women with disabilities. Some of them are or have been President of their national or local-level self-help group, or have served as an executive member of DPI at the national level.

The program participants from the developing countries find common areas and values that they can share with Japanese women with disabilities, so that whatever they learn in Japan can be related to one common set of principles, that is, self-control and self-determination. Both sides come to learn that their problem identified on an individual basis is global. Since the solutions must also be global, an international gathering like this forum should provide international perspective.

#### Supporting Mothers of Children with Disabilities

According to the culturally-defined gender stereotype, the





father's role is to work for the well-being of the whole family. That means he leaves all the duties of child-care in mother's hands so that he can earn much income for higher economic status of the family. Being confined to the house, mother-child relationships become very strong. Accordingly, her affection of and control over a child becomes stronger when he/she has a disability. Her sense of responsibility is reinforced by her anticipation of the child's difficult future. In Japan, the extreme case of a mother's overwhelming love is manifested in the peculiar phenomenon of mother-child suicide, which is still being committed. After the failure of a double-suicide attempt, an excuse the mother often makes is that she does not want her child to suffer alone from the future hardship of life without her assistance and support.

The subordination of a child is intensified when the child is a girl. The preconception of women in the socially recognized role as wife and mother makes them second class citizens. The perception of capabilities concerning women and persons with disabilities develops into a more negative view in the case of women with disabilities.

The mother believes that her poor, dependent child would be discriminated against all throughout her life and, therefore, feels a heavier responsibility towards the girl. For a girl with a disability, womanliness is regarded as something unattainable. Her mother automatically assumes that pregnancy and child-bearing have nothing to do with her. There are two options that mothers traditionally pursue after giving up the idea that their physically-challenged daughters will get married. Some can only think of relegating the girls to an institution where life-long care and protection can be provided. Other mothers force their daughters to exert more effort than their non-disabled friends in order to acquire greater knowledge and skills to support their single lifestyle.

It is always the mother, and not the father, who is blamed if a child is born with a disability in the developing countries where the women's status is very low. In an industrialized country where nuclear families are common, the father often neglects family affairs because of a very tiring working schedule. There is usually the possibility of family breakdown when the mother is left helpless with nobody to consult with.

Mothers' biased attitudes towards their disabled children occur when there is not enough moral support given by medical professionals and other parents of disabled children. Since there are not many medical professionals who can understand the particular despair of these mothers, it is the role of women with disabilities to share her problems and encourage her. They can also offer their expertise in assisting the mothers to start a self-help group.

In a developed country like Japan, women with disabilities in some independent living centers organized a counseling courses for parents of disabled children, especially for mothers. The purpose of the course is to help them recognize the identity of their child. The mothers often take the opportunity to express their child's needs in their behalf. However, their opinions do not always reflect the child's real needs. Their action merely deprives the child of his/her right to speak out himself/herself. Through the course, parents gradually admit and recognize the rights of their disabled child.

### The Changing Role of CBR

One of the reasons why ADI also assists community-based rehabilitation (CBR) in developing countries is that CBR reaches the mothers based on the family-oriented approach. Roles played by the mothers as promoters of the child's spiritual and physical development and of public awareness, as well as advocates of human rights are crucial in the mainstreaming of disabled



persons. The early focus of many CBR projects was in rehabilitation and other medical services based on primary health care. At present, there are also programs in literacy, handicraft production, distribution of basic medicines and self-help devices, income generation program including small-scale credit and business development, and family planning.

### Sharing Experience of Empowered Women with Disabilities

Some women with disabilities in Japan have developed their leadership through their participation in political activities. The main focus of their movement was to eliminate a practice done in institutions, that is, the extraction of wombs against the will of the female residents. It is assumed that this crime is still being committed somewhere in the country because the institution staff feels it troublesome to take care of them during their menstrual period, or because the staff fears that they will become pregnant. Many women in institutions experienced being persuaded or forced to agree to the surgical removal of the womb, and this was permitted under the Eugenic Protection Law.

The first collective action against this was taken when a newspaper took up a case of hysterectomies in which a woman with intellectual disability had her womb removed against her will at a university-affiliated hospital. She and her supporters blamed the government on the grounds that the removal of the womb without the consent of persons with disabilities or their guardians was a clear violation of human rights.

DPI-Japan is one of the organizations who showed the biggest interest in this issue, while a national organization of parents of persons with intellectual disability discussed measures to prevent the recurrence of such operations. The government's responsibility for having ignored the situation is the cause of the problem. DPI-Japan thus started a campaign to protect the rights of persons with disabilities, especially those with psychiatric and intellectual disabilities. As part of their campaign the members of DPI Women's Network in Japan and their supporters, together with the close cooperation with lawyers, called for action to ensure that sterilization would not be permitted on wombs of women with physical and mental disabilities.

Utilizing the pressure coming from domestic and international communities, they finally moved the government to admit that the law was based on the outdated eugenic concept. The revised law took a simplified approach, but it does recognize that the prevention of the birth of so called "inferior offspring" is not allowed any more.

This was the first experience for these women with disabilities to get involved in political action. Although only the conventional methods of meeting, discussion with the parliament members and the Ministry officials, and issuance of newsletters and appeals were utilized by them, victory was achieved. Lessons they learned from this experience are the effectiveness and efficacy of organized movements and the crucial role of self-help groups in development.

The number of women in the present executive committee in DPI-Japan is only 3 among 20. It is sure that their strengthened leadership will change this situation in the near future. In the DPI Asia-Pacific region, the situation is very similar to Japan.

There are only 5 female regional council members, that is 23%. The voice of women with disabilities collectively given from the member countries in the region will also be helpful in reversing this unbalanced situation.

Needed Principles of Development Assistance Programs

In conclusion, basic principles are needed to make all of us



in this forum aware of the significance of international development programs which bring about effective social change. In order to make the program sustainable, we need to keep the following in mind.

Aid programs, both government and non government should be expanded and reoriented in order to address the needs of women with disabilities, especially throughout their life cycle, through specific programs and projects to establish and strengthen self-help activities of women with disabilities.

Women with disabilities must be integrated fully into all levels of development planning and implementation including self-help movements of persons with disabilities. The importance of early gender analysis is emphasized. If development programs fail to secure the participation of women with disabilities, the achievement of the social transformations will not be effected.

In all respects, women must be regarded as men's partner in participating in the decisions that directly affect their welfare. Equal opportunities will make possible the improvements that are urgently needed in the situation of women with disabilities throughout the world. Women and men need to work together to facilitate change.

Literacy training programs should be introduced for women with disabilities. Such programs should be organized in parallel with other appropriate training programs based on women's personal and community needs. They can make an equal contribution to the development process, once given proper training and opportunities.

Efforts should be made to help women receive legal guarantees, rights, protection, and entitlements equal to those accorded to men. In some developing countries, men with disabilities, even as boys, enjoy a higher standard of legal protection than women with disabilities.

Mandatory training programs should be included in the orientation for the staff and field workers in aid programs which enable them to recognize the needs of women and their relationship to development. Discriminatory attitudes towards the role of women with disabilities are, after all, deeply rooted in all cultures, whether in the developing countries or developed ones. The straightforward fact that women with disabilities should be entitled and enabled to contribute to socioeconomic development, is not always easily understood. Training is also needed in participatory and organizational skills to work sensitively with women with disabilities.

Groups of women with disabilities which assist self-help groups of women with disabilities should be given priority in granting funds. Their program is need-oriented, compared with other assistance projects.

The program planners are encouraged to include representatives of self-help groups of women with disabilities in their programs from the drafting stage. It should be recognized that their participation plays a key role in furthering the efficiency and effectiveness of development programs.

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## Running a Small Business: An Experience in Hong Kong

Karen Ngai is the Honorary Secretary of the Rehabilitation Alliance Hong Kong

### Rehabilitation Alliance Hong Kong

#### Nature of the Organization

It is a self-help group which means that its members plan, control and monitor the management and development of the organization.

#### Membership

People with or without disabilities can both become members. Categories of disabilities include people with hearing impairment, visual impairment, physical handicap, developmental disabilities, chronic illnesses and the discharged mental patients.

#### Organizational Goal

To advocate equal opportunities and full participation of people with disabilities in Hong Kong.

#### Major tasks of the Organization

To attain the above goal, to eliminate discrimination, to promote employment opportunities and to create a barrier-free society with and for people with disabilities in Hong Kong become the major tasks of the organization. With materialization of the above goal, it is believed that people with disabilities can also lead an independent and fruitful life as others do.

#### The Employment Issue -

##### Self-employment as a Viable Option

Among the various modes of employment, self-employment is regarded a viable option to create job opportunities for people with disabilities. With gainful employment, people with disability can make money out of it, regain their self-esteem, confidence and control over their own daily living and in return lead a meaningful life according to their own definition. That is why the idea of running our own business was given birth.

#### To Run Our Own Business



## Objectives

?????to demonstrate to the community the workability of people with disabilities

?????to generate money for the recurrent expenses for the Alliance

?????to create employment opportunities for people with disabilities, which will ultimately lead to increase in income, self-esteem, extent of community integration and quality of life of people with disabilities.

?????To demonstrate workability of people with disabilities also help to dispel myths and stereotypes of the public, as well as to educate and serve as a model to other people with disabilities.

## A Pilot Project

Our business is to manage and operate convenience stores by people with different categories of impairment, which is the first of its kind in Hong Kong and the Asia-Pacific region.  
Our Experience

## A Store for All

?????To facilitate our work as well as to enable others including the disabled and non-disabled to use the facilities, a number of adaptations are made in our store such as the Braille directory for the people with visual impairment, more space and handrails for wheelchair-users...etc.

?????Improved accessibility outside the store like stairs and toilets are also modified to meet the special needs of people with disabilities.

?????Staff team of the store also comprises both disabled and non-disabled persons. However, disabled persons form the majority of the team which involves people with developmental disabilities, chronic illnesses, physical handicap and discharged mental patients. There is no difference in salary for both the disabled and non-disabled employees as far as their job duties are equal. In fact, the pay is also compatible to the market rate.

Difficulties encountered and strategies employed

- Difficulties
  - . lacking experience in business management and personnel matters
  - . physical barriers of the environment
  - . recruitment and training problems
  - . public attitude and work attitude of the staff

- Strategies

- . staff development (management)
- . public education
- . education and training for the employees and potential employees
- . advocate for policy change

- Ultimate goal

- . total integration and a society for all

## Conclusion

Although we know that the business is not easy to run and there is still a long way to go before we could achieve our goal, after all, this is a good start. We are willing to try our best and make our every effort to have our idea actualized.



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## U.S. National Study on Women with Physical Disabilities

Margaret A. Nosek, Ph.D. is the Director, Center for Research on Women with Disabilities  
Baylor College of Medicine, Houston, Texas, U.S.

### Negative Stereotypes

I am a woman! It took me many years to understand what that really means. I am a whole woman, but somehow, along the way, I assumed that there were some parts of womanhood that weren't my own. I was anxious to form relationships, but no one approached me for a date, making me feel like a neutral sex. I was raised to expect that I would never marry, making me feel that family life was not supposed to be for me. I was given little information on reproduction except that it should be avoided at all costs. I can't tell you how many times I was told I should have a hysterectomy. It was always my disability that was more important than my womanhood. These were the messages I was getting and I used to believe them.

I am also a rehabilitation researcher, and I leaped at an opportunity that arose through the National Institutes of Health to investigate why this discovery takes so long for some women like me who have physical disabilities. What we at the Center for Research on Women with Disabilities found is that many women around the United States have also experienced negative stereotypes and barriers to understanding and nurturing their womanhood. What we also found is that many women with disabilities have overcome the effect of those stereotypes and have had wonderful success in developing relationships, families, and satisfying lives.

I also wasn't supposed to live this long or this well. From the time I was very young, I assumed that life would be short. The fact that I and many women like me have survived, that many of us have children, and that we are even living with gusto astounds the medical profession. But we present medical science with a number of anomalies, mysterious conditions that defy diagnosis and treatment. Special disability-related needs during pregnancy, premature aging, unexpected responses to standard courses of treatment, and masking of symptoms by disability, frustrate those who are trying to deliver good health care to us. We are a population that medicine does not understand very well.

### Studies

In 1992, we were awarded a three-year grant by the National Center for Medical Rehabilitation Research within the National Institutes of Health to examine the "Psychosocial Behaviors of Women with Physical Disabilities." The enthusiastic response that greeted us from around the country in reaction to the announcement that we were about to begin this study, prompted us to establish the Center for Research on Women with Disabilities. This center is dedicated to conducting research and disseminating information to expand the life choices of women with disabilities.

We began this study by interviewing 31 women with physical disabilities. Based on what we learned from them, we developed a survey questionnaire that went out to more than 2,000 women. About 950 completed the survey and sent it back to us. About half were women with physical disabilities, the other half were their non-disabled female friends. In this way, we were able to separate out problems that are related to having a disability





from issues that we share with all women. Let me tell you about five of the most important things we found:

### Main Findings

First, women with disabilities had severely limited opportunities to establish romantic relationships. Nearly ninety percent had had at least one serious romantic relationship or marriage; but only about half were currently involved in a serious relationship, compared to about two-thirds of women without disabilities.

Second, we found that women with physical disabilities have as much sexual desire as women in general, but they do not have as much opportunity for sexual activity. Ninety-four percent of women with disabilities had sexual activity in their lifetime; but only about half were currently sexually active, compared to sixty-one percent of women without disabilities.

Third, we found that self-esteem in women with physical disabilities is more strongly influenced by social and environmental factors than by the fact of having a disability. More than three-quarters of the women with disabilities had high self-esteem and a positive body image. Whether the woman had a severe disability or a mild disability, incurred disability earlier or later in life, or had ever been in special education didn't make much difference in their self-esteem. It was working, romantic relationships, and abuse that seemed to make a significant difference. As long as women with disabilities were working, or were involved in a romantic relationship, or had never been abused, they had about the same levels of self-esteem as women without disabilities. It was the women with disabilities who were not working, not in a serious romantic relationship, or who had experienced physical or sexual abuse, who had the lowest self-esteem.

Fourth, abuse surfaced as a very serious problem for women with disabilities in this study. We have even fewer options for escaping or resolving the abuse than women in general. Among both women with and without disabilities, sixty-two percent had experienced emotional, physical, or sexual abuse, but women with disabilities experienced abuse for significantly longer periods of time.

Finally, we confirmed what many of us have experienced—that women with physical disabilities encounter serious barriers to receiving general and reproductive health care. Thirty-one percent of the women with physical disabilities who participated in this study were refused care by a physician solely because of their disability. The women expressed strong concerns that their physicians did not know how their disability affected their reproductive health. The pervasiveness of architectural barriers in medical facilities was one of the main reasons women with disabilities did not go regularly for gynecologic cancer screening. More women with physical disabilities reported chronic urinary tract infections, heart disease, depression, and osteoporosis at younger ages than the comparison group of women without disabilities.

### Systemic Barriers

So many of the problems we identified in this study stem from society's response to our disabilities. It's not the fact that we have trouble walking or cooking or speaking that makes us any less a woman. It's the fact that we live in an environment that was built without our needs in mind, and the fact that many people can't see past the physical body to understand our true abilities and value. It's going to be quite some time before we can educate medical professionals about how disability affects our health, and about the importance of making medical care



equally available to us as it is to all women. In the meantime, it's up to us to know what our bodies need and force our way through the barriers in the system until we get what we need for healthy living.

It's going to be quite some time before we can rid our world of violence and end the oppression of women. In the meantime, it's up to us to refuse to accept abuse as the price of survival, and to help our sisters in disability recognize the violence in their lives and learn how to protect themselves.

#### Conclusion

It's going to be quite some time before people see our womanhood before our disability. In the meantime, it's up to us to define our own self image independently of negative outside influences, to establish our own productivity, and to pursue our own relationships.

Now is the best time so far to be a woman with a disability. Society is finally beginning to catch up with some of the changes we have been working on for so long. And the world is finally beginning to know us. We are beginning to find our rightful place in the arts, in education, in religion, in business, in government, in science, and in medicine. And we are gathering from all over the globe to acknowledge our past, celebrate our present, and take charge of our future. When societies make change and individuals make change in their own lives, then you truly have lasting change.

I know how it sometimes wears you down, fighting battles every day, constantly having to pave the way for your own survival and the survival of those you love. But know that we will emerge at a point of fulfillment. And also know that you are not alone in these battles. The totality of our energy and our vision could be quite a force to make change in this world. But even more important is the power of our own definition of ourselves. If you truly believe that you are a woman of value, you gain tremendous strength to forge your way through the most stubborn of barriers.

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#### Finding Our Own Power

Mary O'Hagan of New Zealand, is the founding Chairperson of the World Federation of Psychiatric Users.

I have been asked to speak to you today as a woman and as a person with a psychiatric disability. I speak to you as one of the initiators of the mental health service user movement in New Zealand over the last 10 years, and as a founding member and first chairperson of the World Federation of Psychiatric Users. It is important for you to know that I do not necessarily speak for the wider disability movement or for the whole women's movement. As a westerner, from New Zealand, I do not necessarily speak for people from developing countries. I speak simply for



myself.

## Stripped of My Dreams

I want to begin my talk by telling you about my experiences of my psychiatric disability and as a user of mental health services. From the age of 18 to 26 I struggled for my life with severe, uncontrollable moodswings. When I became a psychiatric patient I was stripped - stripped of my clothing, stripped of my credibility and stripped of my dreams. My paid helpers told me I would have moodswings for the rest of my life and that I may never be fully productive again. They warned me against having children in case I passed my bad genes onto them. They gave me many pills to swallow and sometimes a pillow to sleep on. But generally, although they were usually good people, they did not empathize with my distress or help me regain access to the life I had lost. It was the most lonely, unmanageable and devastating experience of my life. For years I was stuck in the demeaning, vacuous role of passive dependency - without any hope or sense of my own power.

### Finding My Power

Then something mysterious happened. One day in hospital all the meaning in me drained out of me and I lost my self in a formless void. My bed became my raft to nowhere, and I clung to it terrified of losing my thoughts and my self forever into the cold unyielding sea of my depression. Then a myth appeared from the ruins of my despair and I recited it like a long lost prayer.

An old woman and her granddaughter lived by a great ocean. Every day the old woman went fishing. She yelled in awe to the ocean 'Great ocean, let me take the life out of you with my net.' She always returned with fish and cooked them for herself and her granddaughter. One day she gave some of the fish to her granddaughter and said 'Cook these for yourself'. The girl wailed 'I can't'. The old woman replied 'You must find your own power'. But the girl didn't understand and went to bed hungry. That night the girl woke from her dreams to a booming voice from the sky 'You have the power of the old woman and the great ocean flowing from the core of you. Now take meaning from the rawness of life and cook it for yourself without fear'.

While my mental health guardians skated across the surface of my pain making small scratches with their inadequate science, something deep within me saved my life by telling me to find my own power.

That was over 12 years ago. Since then, in my own recovery and in the work I have done in the mental health consumer / survivor movement, I have continued to learn how to find my own power.

## On Back Porches

The mental health consumer movement is on the fringes of the disability movement but we have many issues in common. If we think of society or our communities as a house, we could say that people with disabilities have been excluded from the house. In the era of institutionalization we were thrown into the junk shed at the bottom of the garden. In the era of community care we have been allowed to live on the back porch of the house but we are still not invited back inside the house. But the message of the disability movement is that we have the right to live inside the house and it is an abuse of our rights to leave us in the junk shed or on the back porch.

In recent decades several groups that historically have been relegated to a junk shed or back porch existence have demanded a room inside the house. The feminist, civil rights, gay, indigenous and disability movements have asserted they do not





want to be segregated or forced into a mold they don't fit. Instead, they claim, society is the one that needs to change - to give people the power and resources to determine their own identities, lifestyles and cultures.

### Analysis

After my moodswings stabilized over a decade ago I developed a new analysis of the situation of people with psychiatric disabilities, very similar to the typical feminist analysis of the situation of women, which went like this:

- People who use mental health services are oppressed.
- Society and the mental health system do the oppressing.
- Consumers need to get together to raise their consciousness and organise to fight their oppression.
- Society and the mental health system will never meet our needs or allow us to determine our own lives unless it goes through fundamental change.

This is a worthwhile analysis and I still agree with it, but it no longer totally reflects the complexity and ambiguity I have encountered in trying to understand my own power and the power of others.

Every social movement starts with a small band of radical visionaries who are more to be admired for their innovation and clarity than for their complexity or practicality. But at some point, social movements in order to progress need to interact with the world they mistrust - with all its barriers, impurities, offerings and seductions. At this point there is often a split between the radical separatist abolitionists on one hand and the moderate bridge-building reformers on the other. The moderates often spring into existence when mainstream society begins to respond, usually in an inadequate and tokenistic way, to the challenges laid down by the movement. My own view is that a mature movement needs to create a powerful place for both.

It interests me that all the social movements that I'm familiar with begin by highlighting their oppression but eventually generate a new and often unpopular voice that says "Let's stop wallowing in our victimhood and blaming others, we need to get going and do something about it ourselves". This voice has emerged in recent years in the women's movement and in the mental health service user movement. Although the carriers of this message can be very hard on their peers and fail to acknowledge their debt to the originators of their movement, the message itself is a crucially important one.

### Understanding Oppression to Be Able to Use Power

As women and as people with disabilities we must acknowledge and understand our oppression before we can use what power we have to overcome it. But it is very important that as a movement and as individuals, we don't stay stuck in the powerless, oppressed roles that we are used to and often very good at. It is equally important that we can see beyond the sometimes simplistic slogans and orthodoxies we have created ourselves.

I now want to share with you some thoughts and examples of the difficulties those of us who have been in a victim role can have in claiming our power - and by power I mean our ability to make things happen. For this I draw on my own experience and feminist Naomi Wolf's latest book *Fire with Fire* (1).



Firstly, sometimes we assume that people with power over us are intrinsically bad and the disempowered are intrinsically good.

Many of our images of oppressed people show them as innocent victims, as noble or beyond criticism. Naomi Wolf writes that feminists "have developed a belief system in which all evil - from environmental desecration to meat eating to child abuse - is seen to derive from the will to power which is confined to men. . . this belief system describe[s] men as villains and women as saints" (p 144). She argues that the oppressive things men have done to women cannot be explained by their gender but rather by their humanity.

Likewise, I have often had to remind myself, that if I had been a mental health worker instead of a service user, I may have been some or all of the things I have criticised them for.

Secondly, sometimes we do not recognize the power we have.

Naomi Wolf suggests "Women are fed up with reminders of their own oppression. We are moved far more effectively by appeals to our strength, resourcefulness, and sense of responsibility" (p 37).

But often we fail to see ourselves in this way. For instance, recently I visited a project in Newcastle, England where a group of consumers gave advice to the purchaser of mental health services. The consumers said the whole project had been a waste of time - their involvement hadn't changed a thing. Then I talked to the manager who sincerely believed that the consumers' involvement in the project had brought about some very important changes. If others perceive us as having power then we have it even if it is not the degree or kind of power we want.

Thirdly, sometimes we fear the power we have.

Naomi Wolf says "women can't change the world until they can become comfortable with using power, and with understanding how powerful they already are" (p 236).

Those of us who have experienced oppressive power may become suspicious of any power, and lack role models for the wise and responsible use of power. I have experienced this struggle myself as a leader in the user movement when I have at times underplayed the power I have had with my peers for fear of being accused of behaving like an oppressive mental health worker.

Fourthly, sometimes we use our power oppressively.

A few years ago I visited a consumer run housing project in the USA. Instead of walking into a homelike community of survivors I walked into one of the most authoritarian, institutionalized places I've been in. The person in charge showed us around the house and barged into people's rooms without asking them. All the bedroom doors had numbers on them and even the bedheads were numbered. There was a glassed in office downstairs for the staff. In it I saw a notice which read "Barry was caught smoking in his room. Give him only one cigarette at a time". And finally I saw that the staff had a separate toilet from the residents - a sure sign of the hierarchical distance between them. This is an extreme example of a consumer run service that mimics the systems that have oppressed us. But it is a warning to us all that being oppressed does not make us immune from becoming oppressors. In fact there is considerable historical and psychological evidence to suggest otherwise.

Finally, sometimes we have difficulty accepting the responsibility that goes with power.



I have come across some consumer-run services that flounder and fail because the consumers in their new role lack the skills or a sufficient sense of accountability required to handle large sums of money.

I also once worked on a project at the local health purchasing authority where a group of consumers purchased some consumer run new initiatives with the mental health manager. A conflict arose between some of the consumers and the manager. In their new role the consumers had difficulty sharing responsibility for the conflict. They reverted to blaming the manager whom they saw as much more powerful than they were, I believe unrealistically. The consumers also had to make some hard decisions which did not make them popular with some of their peers.

In highlighting our difficulties in claiming power I don't want to pretend that the people who traditionally have held the power, such as men or the mental health system, will give it up without a struggle. As representatives of the various disability groups we have a difficult set of roles. We need to stay in touch with the powerlessness experienced by ourselves and our peers. We need to recognize and use the power we have acquired, to increase the power of all people with disabilities. And we also need to recognize and deal with the forces that continue to deny us power.

I now want to return to that day many years ago as I clung to my hospital bed in despair. On that day, finding my own power simply meant hanging on to hope and a basic belief in my own worth. Since that day I have learnt many lessons about the slippery, complex and ambiguous nature of power. Finding my own power, and making the way for others to find their own power, has been a journey as much as a destination. Over the years I have become increasingly aware that the journey requires much difficult soul-searching and change, not only from those who oppress but from the oppressed as well.

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## The Independent Living Movement in Japan

Masako Okuhira is the President of the Japan Council of Independent Living Centers

There are presently 68 independent living centers in Japan. They provide the services of Personal Assistants, Peer Counseling, Independent Living Skills Programs and others. It is still a new movement, but is growing very fast. I will introduce the Independent Living Movement in Japan including the history, current situation and the future.

The disability movement in Japan has a long history of fighting for equality before the independent living movement. In the 60's, disabled individuals, mainly persons with cerebral palsy stood up to get assurance of living. This movement became big and was called the "Blue Grass Group". They tried to get out from institutions and live in a community with the help of volunteers. Some of them formed communes and





lived together. Their daily living relies on volunteers. However, they always had trouble to find and retain them. The ideology of their movement was criticism and impeachment of the current national approach to disability issues. They insisted that the solution of issues were not their task. During their long movement, they were split into small groups. Some people separated out from the volunteers.

#### The History of IL Movement in Japan

During 1981, the International Year of the Disabled, the cultural interchange of disabled cultures between Japan and western countries were growing prosperously. Many disabled leaders visited the US or other countries which were ahead of Japan in social services for the disabled. They came back home with quite valuable experience and information. The first independent living center in Japan was established in 1986. It was run by the disabled leaders who learned IL Movement in the US. They based their ideas on a model of American IL centers, but it was also very original. Since then, disabled leaders have founded IL centers all over Japan and began to appeal the needs of IL centers for disabled people to live in a community.

The Japan Council on Independent Living Centers (JIL) was established in November, 1991. The disabled leaders from 10 IL centers discussed the needs of having a council to spread the independent living movement in Japan. The philosophy of the IL Movement has won the sympathy and support of many disabled individuals, especially persons with physical disabilities.

#### Current Situation

The Movement is growing very fast. Now not only physically disabled, but also developmentally disabled people work together. As a result, there are 68 centers as of May 15, 1997. But we have some problem. The idea of providing services by disabled people themselves is still new. Also, many disabled people don't have enough experience to manage an organization. Only a few people know how to run offices and provide services. Also, there are differences financially, therefore, it raises much difference in quality.

During 1996, three IL centers in Tokyo were entrusted with a project by the government. More IL centers will take the project. That means the government is recognizing the movement and services of IL centers.

It is very important for us to learn how to manage and provide services. Also, we have to believe that our providing services is best for the disabled population and take pride in our doing so.

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### Creating Legal Inroads for Equal Opportunities in Costa Rica

Alejandra Poveda is the Founder and President of Asociación de Mujeres con Discapacidad de Costa Rica (Costa Rican Women with Disabilities Association)

### Important Considerations

Costa Rica has a little bit over than three million inhabitants. Estimates hold that there are around 300 thousand people with disabilities. Parents and people with disabilities have formed nearly 100 organizations. Although the oldest of these organizations are at least 20 years old, they amount to



relatively few members. The non-profit NGO's comprised of people with disabilities neither have a minimum permanent staff nor an office to serve as an operation center, and the functioning personnel to carry on daily functions relies on volunteer work done by their Board of Directors.

Taking into account the present context of the social and economic policies of the Programas de Ajuste Estructural (PAE) [Structural Adjustment Programs] that limit the access to all services in general, the low purchasing power of individuals, and that the traditional practices by which organizations have managed 'assistance' as short term charity instead of long term development of real solutions, the result is the faster collapse of relief type of operation. The relief model does not seek a long term self-sufficient solution and tries, among the more vulnerable groups, to lessen the harshness of life conditions. Under this model, people with disabilities have not seen improvement in terms of employment, housing and other social conditions.

Social conditions among people with disabilities -most of them unemployed, with poor educational level- increase the urgency for the need of NGO's activities so as to promote better living conditions from the development point of view. Government Organizations that provide help for people with disabilities, until now, have understood the NGOs as a low cost means for the institutional transference of funds -mostly for food and clothing, not in cash- towards people with disabilities.

Based on this situation, it is easy to maintain that People with Disabilities' Organizations, in the best of cases, still are in the transition process from the 'assistance' or 'relief model' to the self-sufficiency model. In terms of presenting legislative proposals, organizations have advanced very little in the field of training people with disabilities.

Costa Rican society in general and, specifically the people with disabilities movement do not still understand such concepts as 'diversity'. Just to name an example, I must focus on the unifying concept of the word disability, but at the same time to its components: men, women and children, teens and elderly, variables as economic situation. There also are other groups of people with disabilities that usually become invisible to society as those in jail, and the refugees. We should neither forget the ethnic groups or those who have chosen different sexual options. In many countries, there is a pronounced prevalence of factors that influence the population with motor disabilities and, within this, those in wheelchairs in relation to other disabilities - like mental, and those so called invisible disabilities such as learning, speech disorders, cancer, diabetes, epilepsy, arthritis, etc.)

History indicates that power has been controlled by men. In spite that in most cases of mixed organizations it is women that bring the groups together, their work centers mostly round support activities in terms of "women's" chores and is somewhat separated from the philosophical, political and ideological framework. Many of these conditions are socially imposed, a fact that results in an even more reduced participation.

Although the organized movement should represent and empower all individuals, women with disabilities have less opportunities to participate and achieve changes. Even in these conditions, women are starting to organize themselves at a national, regional and international level. The organization to which I belong is such a case: Asociación de Mujeres con discapacidad de Costa Rica (Women with DisAbilities of Costa Rica Association). Even though we have been working since Lizzie Mamvura, the Zimbawan born activist with disabilities visited us in 1993, this organization was founded in 1995. It was the first organization to break away from the traditional model used in the country until then, where people organized around the medical model, e.g. around a specific disability. Ours instead, has a more inclusive aim organizing all disabilities and at the same time offering space to women with





and without disabilities.

## The Legal Context

The basis of jurisprudence concerning disabled people is based mainly on the last 200 years of history. It covers the general living conditions, and social and economic jurisprudence from different eras. It has evolved from the rendering of basic care in institutions, to children's education and to rehabilitation of adults with disabilities. Terms like 'integration' and 'main streaming' came about after the World War II.

By the end of the 1960s, the people with disabilities organizations from some countries had started to define a new concept of disability based on struggles for recognition by civilians and soldiers that acquired disabilities, women's groups and "hippies". At the same time, in the developing countries, the link between poverty and disability came to the fore.

The 1980's heralded the recognition that people with disabilities also have human rights which were publicly consolidated in the Standard rules for the Equalization of Opportunities for People with Disabilities, approved by the United Nations in 1993. These Rules were written to guarantee that boys and girls, women and men with disabilities, as members of their respective communities have the same rights and duties as all.

This document is based on four requirements for equal participation: greater awareness, medical services, rehabilitation and support services. It requires 12 areas for equal participation: access possibilities, education, employment, income protection and welfare, life within a family and personal integrity, recreation and sport activities, religion, plus ten measures for enforcement.

Conditions in various countries demonstrated that a legal document was needed to introduce social changes. Costa Rica is renowned for its respect of law. There is quite an amount of laws that protect citizens. In the recent past, the tradition was to pass legislation on small items about disability, and it was mostly protectionist. In spite of that, daily life indicates that there indeed exists discrimination towards disabled people in practice; but not by law.

Equality before the judicial system might be an example of that. Even though the "Right to Vote" is given by the Political Constitution, the rights of disabled persons are violated for numerous reasons.

The present government, led by Mr. Figueres, made campaign promises to introduce a law for people with disabilities. Moreover, it was the first government in history to name a Presidential Advisor for People with Disabilities Affairs. Named to the position was Mr. Alvaro Mendieta, a Government Affairs specialist who is himself a person with disability. Even though there were some other unsuccessful bills, the Act on Equal Opportunities for People with Disabilities, known as Law 7600 was a result of this political conjuncture.

A relatively small committee of technical personnel, between 5 and 10 persons, was responsible for this Bill and were appointed with a special sense of 'representation' since the Federation of People with Disabilities representative had the legal support of only one organization. There were no public meetings in which parents and people with disabilities organizations could express their points of view, and this - as I see it- is one of the major weaknesses this law has. The lack of political process to educate the population with disabilities is another.

In spite that our organization sent texts to substitute those in the Bill referring to women, e.g. child-care, adapted for women with disabilities medical services for family planning,





etc., were not taken into account. Since Law 7600 is lacking in terms of topics on domestic and sexual violence towards women with disabilities, forced sterilization with no consent from the woman with disabilities and undertaken to suit other people's needs; but performed to supposedly protect them from sexual abuse.

Within the norms of the Standard Rules, Costa Rica approved Law 7600 in May 1996. No doubt, it is an important document to transform society within millennium's reach. Its goals are:

a) Be an instrument for people with disabilities so they can reach their maximum potential, their full social participation and the exercise of rights and duties established by our legal system.

b) Guarantee equal opportunities for Costarican population in areas such as health, education, work, family life, recreation, sports, culture and all other established areas.

c) Eliminate any kind of discrimination towards people with disabilities.

d) Establish the legal and material basis to allow the Costarican society to adopt the necessary measures for the leveling of all opportunities and against the discrimination of people with disabilities.

Within its main principles, it addresses the State's, family and organizations of people with disability obligations, among others.

The first chapter refers to education. The second is on labor, the third refers to health systems, the fourth is on physical space, the fifth is on the means of transportation, the sixth refers to communication and information and the seventh, to the access to culture, sports and recreation.

#### Impact on the Media

The reaction that media had and specially the written press deserves some consideration. Usually, when referring to the issues involving people with disabilities the written press does it in a "merciful" or charity-oriented phraseology. In spite of efforts to change this perspective, there still are erroneous ideas on the subject.

One example deals with some comments by a labor group headed by special education teachers. Many of these workers thought that this bill was aimed at the dismantling of the special education structure in the country. Added to the discussion on privatization processes and protest movements by some labor groups against it on the national level, the teachers actions appeared to be an over-reaction. Even though the law speaks to the mainstreaming process, the teacher's reaction created a negative scenario towards it. The December 4, 1995 Editorial from La Prensa Libre is an indication of this polarization.

The media's task is to elevate this collective discussion to a social level and to a social debate. The community pressure processes usually start as a private issue that transcends through the means of communication onto the public sphere and social awareness.

#### Recommendations

1. A law usually is the beginning of a road. There is a long way to go so as to achieve an active citizenship by people and, specially, by women with disabilities.

2. For a law to succeed, there is a need to transform the



concrete aspects that have influenced the underlying conditions: ignorance, abandonment, superstition and fear. These, among others, are social realities that throughout history have segregated people with disabilities and fettered their development.

3. Disinterest and reaction by some functionaries responsible for their implementation, together with ignorance on the law and rights, and the privileges it offers can endanger the social impact of this Law.

4. Collective participation must be encouraged: local organization is needed including in the rural areas.

5. A very important element is the link with other institutions, governmental and non-governmental, national, regional or international.

6. It is very important to have access to information and data that supports our demands for equal opportunities. Socio-economic and policy studies on the situation of people with disabilities and, specially about women, must be encouraged.

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"Stepping out of the Circle": disabled women in Yugoslavia moving towards independence

Gordana Rajkov is the President of the Center for Independent Living of Belgrade, Yugoslavia

#### Summary

The present state of Federal Republic of Yugoslavia-FRY, is what remains from the Former Yugoslavia, when most of its constituent parts decided to separate and form independent states. This process which started in 1991, with the war in Croatia, followed by the war in Bosnia, was tragic and painful for millions of people who lost their lives, families and homes.

Although the countries which were directly at war suffered the most, the surrounding countries were affected as well. UN sanctions were imposed on FRY in 1992. In this country, to which over 3 years 1 million refugees have fled the war and the sanctions had devastating consequences. The increase of poverty over the past 5 years, from 6% to 40%, combined with a decrease in real expenditures on social services, has left millions in an extremely vulnerable position, particularly groups such as disabled people, with limited access to employment and social services support.

Throughout the FRY, associations of disabled people are impairment specific and their approach is based largely on a medical/charity approach. They have a long history of support by the state that continues to influence the way in which they work today. On the other hand, in Belgrade there is a number of impressive women's groups, many of which were formed in the early 90's by feminists who decided to respond to the social, political and economic crisis. However until recently, neither of the two kinds of organizations -women's and disabled people's-had in their agenda the issues of women with disabilities.

The Center for Independent Living in Belgrade, that was set up in 1995, is the first cross-disability organization in FRY. We established a women's group within the Center in June '96. The main goal of the group is raising awareness on disabled women's issues and working towards their empowerment and independence. We have chosen to work towards achieving this goal through a three-pronged approach:



(1) working together with women's groups in Belgrade, who are already utilizing the basic rights and empowering women's approach; (2) empowerment of disabled women that are participating in these activities; and (3) raising awareness in the associations of disabled people.

To date these activities have consisted of including disabled women in the volunteers' training at the SOS hotline for women victims of violence, which has had an impact both on disabled and non disabled women participants, changing their perceptions on women's and disability issues.

A number of lectures were presented by disabled women at the Women's Studies Center for non disabled women students. A series of disability awareness raising workshops were organized in the Autonomous Women's Center, some of which were facilitated by disabled women from other European countries. As a result of all these activities a Hotline support group for disabled women-"Stepping out of the circle" was set up in March '97, run by disabled women from Belgrade CIL.

Through all these activities, disabled women have started building up their capacities and acting as catalysts for change. The inclusion of women from different associations of disabled people, has brought the issue indirectly to the associations of disabled people as well. However, new skills and knowledge that disabled women have gained through these activities, will not be completely productive, until appropriate services, such as personal assistant services are provided in Yugoslavia. At present CIL is looking for funding for a pilot project to set up a Personal Assistance Service in Belgrade. Once that project starts, it will provide more opportunities for disabled women activists to put independent living fully into practice and prove that disability can be an investment and is not a burden to a society.

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## Eugenic Ideology in Japan

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The Eugenic and Maternal Protection Law was finally changed into The Maternal Protection Law in June, 1996. The above-mentioned Eugenic and Maternal Protection Law aims at "Preventing the birth of inferior offspring", clearly stating that the medical doctors should perform 'eugenic operation' 'sterilization on people with a mental illness or hereditary disease, which clearly indicates the violation of human rights.

We, as individuals with disabilities, unconsciously regarded ourselves as less-valued people, and our pride and dignity were reduced as a result. Moreover, for women with disabilities, their reproductive rights were denied, and there are a number of female disabled individuals who were forced to have their uterus removed by the judgment of their families or staff of their institutions. The revision of the Law mainly results from the international condemnation on

this issue, that are based on protests from the members of DPI women's Network. They revealed this inhumane legal system to the international community at the World Conference on Population and Development (1994, Cairo) and the NGO Meeting of the UN World Conference on Women (1995, Beijing).

Furthermore, the Law itself is contradictory to the Plans for the Disabled, issued in 1995 based on the Fundamental Law for Countermeasures for Mentally and Physically Handicapped Persons. Accordingly the articles on eugenic ideology or eugenic operations in the Law were all eliminated, and it simply stipulates those articles on women's sterilization and abortion.



However, the problem still remains that the government named the Law "Maternal Protection Law" despite the opposition from women's groups, and the Law doesn't protect the right of women's self-determination on abortion.

Moreover, within a year of this revision of the Law, it was reported that some doctors' groups were considering making suggestions to the government on introducing an article on the fetus (that the abortion can be performed if the fetus has some disabilities) to this law. We then sent letters of objection to this article, together with other women's groups to respective organizations. Consequently, the doctors' groups categorized this issue as requiring ongoing discussion, and made their board members' announcement that they wish to raise an issue to the society on prenatal genetic diagnosis.

In 1995, WHO announced the guidelines on genetic treatment. UNESCO also plans to adopt the Declaration on Protection of Human Genome at its coming general assembly in 1997 Autumn as human genes are common property of the human race. If this Declaration is ratified, we expect that the domestic laws on genetic research and treatments will be organized in the near future. We fear most that the majority of the genetic treatment has been geared towards the elimination of disabled people.

We have recognized ways to enrich our lives, regardless of the degree of our disability or length of our lives, by seeking help, mutual understandings, and improving the society.

We wish to form an international solidarity among women with disabilities towards a barrier-free society, to inform the whole world that there is no need to fear giving a birth to a disabled child, and also to prevent eugenic ideology from prevailing over the legal system of genetic treatment in each nation.

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#### Feminist Bio-Ethics & Disability

Marsha Saxton, Ph.D., is a teacher of disability studies, University of California at Berkeley and a member of the working group on the Ethical, Legal and Social Implications Program of the U.S. Human Genome Initiative, National Institutes of Health.

I have been working on women and disability issues for many years and am particularly interested in the connection between women's health and disability issues. I teach Disability Studies at the University of California and work with the World Institute on Disability.

First I want to tell you about my own history and how I got into this work because it helps me to connect with other women. We must tell each other what our lives are really like. Then we can go on to make the world better for everyone.

#### Background

In 1951 I was born with spina bifida. My parents were told that my birth was a tragedy and if they wanted, I could be put away in an institution, so they wouldn't be burdened with my care. My parents wanted me and took me home and loved me like any child. But many other babies around the world with spina bifida, and other disabilities were not taken home and loved. Things have gotten a little better in the last fifty years. Unfortunately, the birth of a baby with a disability is still regarded as a terrible tragedy. Those of us born with disabilities carry this negative message all through our lives. Those who become disabled or get sick later in life are hit with the negative message that we no longer whole, not fully human. In 1958, when I was seven years old I went to Shriner's Hospital



for Crippled Children in San Francisco to have surgery to correct muscle weakness in my legs. I would return there for many months at a time to have more surgeries during my childhood years. I felt scared and alone at the hospital. My parents were not allowed to visit. The nurses and doctors tried to help us walk better. Some were kind to us and some were not. But we got the message that we had to be fixed to become acceptable people. One nurse told me, "God made you cute and happy to make up for being crippled." This message made me feel like I could never tell anyone about my pain, or how scared I was. A doctor told me, "This surgery is very expensive. You should be grateful. Without it you would be crippled all your life." I heard the message that to be crippled is a terrible thing. Another message was that even though this surgery and hospitalization felt like abuse, I should be grateful.

When I was in the hospital, I wanted to become a doctor, because I saw that the doctors had power over the nurses and the patients. I also saw that I wanted to make medical care better and help children be treated better than I was.

Many years later, in 1971, when I was in college, I was browsing in a bookstore on the campus of the University of California. A new book, *Our Bodies, Ourselves* caught my attention and I leafed through it looking for parts of the book which referred to my experiences as a young woman with spina bifida. I looked for issues about body image and sexuality. I didn't buy that book. I felt like I didn't find my body or my life in that new book on women's bodies and lives. Then in 1979, only a few years later, some friends and I worked with the authors of *Our Bodies, Ourselves*, to rewrite the chapters on body image, sexuality, birth control, motherhood, reproductive technologies, and social action to include information about disabled women's needs and experiences. Now, more and more, disabled women expect to be included in any book on women's experience and women's health.

In 1988, some friends of mine and I started an organization in Boston called The Project on Women and Disability. We provided support groups and empowerment training for disabled women and education for doctors and women's groups about disabled women's health issues. We heard from many disabled women around the world, many were starting similar kinds of groups, still very small, but we were beginning to get connected, to feel a sense of an international network of disabled women.

## Feminist Bio-Ethics

I didn't become a medical doctor but I am still devoted to changing the medical system. I am now interested in a field called bio-ethics. Ethics is the study of good and bad practice in a profession or field of study. Bioethics studies the ethics of biological medical science. Bioethics tries to figure out what is good or bad about medical treatments and technologies, and how to prevent people from getting hurt by being used as research subjects.

There is a small but growing group of women creating "feminist bioethics." Feminism means many different things to different people. To me it means women working toward equal power in the world. In feminist bioethics we are trying to understand how discrimination against women can affect medical technologies and medical treatments, and how women's views and experience can help medical science become more humane and just.

There are several different issues that feminist bioethics is just beginning to study. I would like to tell you about them:

### Reproductive Healthcare

Disabled women are still not being treated like "real" women with "real women's bodies" in all parts of the world. Many disabled





women are still not being offered birth control. Others are being forced to use birth control or sterilized against their will. Disabled women are still not being asked what we want for our healthcare. Doctors are not trained to realize that a woman with a disability may also be sexual, might get cervical or breast cancer and need screening or treatment, may also have menopause. This is disability discrimination. We want to make sure that disabled women are treated like women, with women's bodies, with women's sexuality, with women's needs for quality healthcare. We want women's health groups and clinics and reproductive rights organizations to recognize disabled women's needs as important.

### Disabled Women as Mothers

Many disabled women are mothers and deserve respect for their motherhood. Many disabled women are told that they could never become mothers because they would be incompetent or would pass on their disability. These are old and oppressive ideas. This is disability discrimination. We want to make sure that disabled women can have babies if they want to and raise them if they want to. We want to create services and financial help for mothers with disabilities to care for their own children, and also to have access to adoption. We want disabled mothers to be treated with respect.

Motherhood and good healthcare for our female bodies are issues that all disabled women struggle with around the world. In the last ten years or so, in the U.S. in women's books and publications, the issues of disabled women are just beginning to appear in the list of represented groups. We've made it to the list. But we have a long way to go to really be included and understood.

### Prenatal Testing and Selective Abortion

Prenatal testing means using medical tests to determine if a baby might have a genetic condition. In many highly industrialized countries, including the U.S., European countries, Canada, and in Japan and China, genetic research is growing very rapidly. The Human Genome Initiative in the U.S. is funded with 3 billion dollars over 15 years, to eventually make a map of all human genes. Scientists expect that out of this will come tests to detect every genetic disease. But cures are much harder to create than diagnostic tests that can only identify a disease and label it. Cures for most genetic diseases are still decades or even centuries away.

We know that most disability is not the result of genetic causes. Most disabilities and diseases are the result of poverty and hunger, accidents, war, virus and bacteria. We should ask if it makes any sense to spend so much money on genetic science when reducing most disability and disease could come from fair sharing of medical and economic resources. But in the U.S., healthcare is a big industry. Genetic science is well-funded and there are new genetic discoveries every day. Many women are being pressured to use these tests to find out if their unborn baby might have a genetic condition. Then they are encouraged or forced to have an abortion to avoid a baby that would become a disabled person. This is a high-technology version of disability discrimination.

We want to make sure that all women understand that they can refuse to have these tests if they don't want them. We want to make sure that no doctors or insurance companies or governments are forcing women to use tests and then forcing them to have abortions if they don't want to. We want to make sure that companies that make big profits from selling tests are not the ones influencing public policy or creating medical standards of care, policy that supports their economic interests. Unfortunately, this is already happening in the U.S.



We also want children with disabilities to feel welcome in the world, as we want all children to feel welcome, not for certain characteristics, but simply because they are born and we love them for whoever they are.

### Physician-Assisted Suicide

Another important issue is physician assisted suicide. Disabled people are valuable human beings and deserve to live good lives as long and fully as possible. But many people with disabilities are often isolated from others, live in poverty, and have been told they are a burden to their families and to society. People in this situation will sometimes feel like death is the only way out. Sometimes doctors and family members don't understand that disabled people's lives are so hard because of discrimination. They can't tell the difference between the pain of disability and the pain of terrible social mistreatment. Many people cannot distinguish between severely disabled people and people who are dying. Some doctors are encouraging people to die before their natural death by giving them lethal doses of drugs. Sometimes when severely disabled children are killed is called "mercy killing." This is not mercy, it's killing and it is the worst kind of discrimination.

Many have heard about Dr. Kevorkian in the news. He has facilitated the deaths of many people who felt like they wanted to die. Some of the people believed they were already dying. Some of them were disabled people who were not dying but felt alone and hopeless and unable to fight for their rights as disabled people. Some felt like a burden to their families. The people Dr. Kevorkian has killed are mostly disabled women. This is a form of disability and gender discrimination.

We want to make sure that disabled people or any sick or old or young people are never encouraged or forced to die to save money, or save trouble for their family. We want to make sure that disabled people have the resources and self-determinism to direct their own lives as best they can, so they can feel like valued citizens. We want to make sure that disabled people who feel terrible about themselves have a chance to understand that discrimination causes these bad feelings, and have the option to meet other disabled people who love being alive. There is a new organization in the U.S. called "Not Dead Yet" that is organizing to resist physician-assisted suicide. We want to make sure that if this idea of physician-assisted suicide starts happening in more countries, disabled people are organized and ready to resist.

### Training Medical Providers About Disability

In order to make progress on these "bioethical problems" doctors must get training in disability issues. A favorite part of my work is teaching doctors, medical students and other healthcare providers about disability by having them meet disabled people outside of a hospital or clinic setting, and have them really get to know us as people. It is a way that healthcare providers can learn that disabled people are not "patients" but are people who can be resourceful, interesting, funny, smart, loving, ordinary citizens, maybe even friends. They can learn that people with cognitive and mental disabilities have much to offer their families and the world and are not just "a burden." We want doctors and others to understand that disabled people are the experts about disability. Also disabled people can realize that they can be peers and mentors to medical providers and have a lot to teach them. This is very empowering to disabled people.

Medical providers can begin to understand that it is discrimination that makes disability much more difficult, and that empowerment and respect make disability much, much less



hard. This idea is very new and very few schools are open to it. I would like someday to see disabled people teaching in every medical and nursing school around the world. It may not happen in my lifetime, but I think it's such a good idea that I expect it to happen someday.

#### Need for Mentors

It is very important for disabled women to meet in groups about health issues, to hear others and talk and understand how discrimination works. It works best with a range of different disabilities, including older and younger disabled women and girls whenever possible. Disabled young women and girls have a great need for "big sister" mentors. They are our hope for the future leadership of our community.

#### Conclusion

It is 1997, and we are here together. Meeting you disabled women and friends and allies makes me feel proud that I belong to this world wide group. It also reminds me of when I was a little girl with the other disabled girls in Shriner's Hospital. But we are no longer in the children's hospital. We are powerful, smart, effective leaders of our own movement. I wish I could go back in time and tell those little girls about this conference, tell them that we will have this knowledge and power and connection and hope to offer each other someday. In a way, we do that whenever we meet a young disabled girl or woman and offer her a new way of facing the discrimination, with new knowledge and resources and a whole world of other strong disabled women connected and supporting each other.

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## Communication and Technology: Women's Work

Katherine D. Seelman, Ph.D., is the Director of the U.S. National Institute on Disability and Rehabilitation Research , a federal agency.

## Introduction

The National Institute on Disability and Rehabilitation Research, which I direct, is a modest, but unique research institute in the United States government, and perhaps in the world. NIDRR has a limited budget, but it, too, has a bully pulpit with which to address the interests of the disability community in science and technology. NIDRR, as it is called, is a bridge between the scientific and the user communities. On the one hand, a user may need faster speech from an augmentation communication board. On the other hand, the new knowledge required for faster speech may be located in a basic research laboratory remote to the user. How to bridge the need for knowledge by a disabled consumer with knowledge which was designed for use by the military or by the space program? NIDRR's own research engineering centers serve as a vital link. An engineering center can take on the problem of faster speech, locate some of the basic science solutions and adapt them to the needs of the disabled consumer. NIDRR is committed to transforming the advocacy Independent Living/Civil Rights agenda into a research agenda which will result in a more accessible society and a more accessible world. NIDRR does this by supporting a research agenda developed by the consumer and





scientific communities and by effecting change in national and, sometimes international science and technology policy. NIDRR also supports advanced training of new researchers, especially individuals with disabilities. Much of NIDRR's research information is available on the NIDRR website (<http://www.ed.gov/offices/OSERS/NIDRR/nidrr.html>) and electronically or on paper through the National Rehabilitation Information Center (NARIC) (<http://www.naric.com/naric>, 800-346-2742.)

### Why Should the Disability Movement Be Involved with Science and Technology?

The Movement has fought for the rights of exploited people for a long time. This is the Information Age, the Age of Technology. In this age, justice questions often come wrapped in electronics, genetic engineering and toxic substances. Unwrap them and you find, hunger, disease, illiteracy, unemployment and exploitation of the weak. Unwrap them and you will also find instruments which can be used to alleviate these age-old problems. Only human choice-human advocacy-can determine the distribution of technology resources.

For individuals with disabilities, technology has a special significance. One civil rights activist put it this way:

"For Americans without disabilities, technology makes things easier. For Americans with disabilities, technology makes things possible."

Science and technology involves a lot of money. Every country in the world is involved in some aspect of science and technology. Quite frankly, without disability advocates in and outside of government, the government and the corporate sectors will not know that they should use their resources to support accessible products, accessible transportation, accessible housing and accessible telecommunications. Without advocates, government and the corporate sector will not assure that technology is available on the basis of need not wealth. Without advocates, health ministries will not support technology for living independent lives and will not support the collection of statistics about disability. Without advocates, education and social service ministries will not support accessible technology for school and work. Without advocacy, ministries of foreign affairs and ministries of commerce and NGOs will not support the incorporation of universal design into technical standards for products. They will not support economic development projects to build and distribute assistive technology which is appropriate to a particular culture and landscape. Without advocacy, the science and technology community will not produce the knowledge base necessary for independent living.

### Our Small Village

This conference is like a village. Each of us has a role in the research that has been conducted. Research is being conducted by all of us for transformation into a common research agenda and to develop research skills with which to replicate the research process in other countries and regions of the world. Upstairs in the Internet Cyber Cafe, people who are advocates, researchers, government employees have banded together. They have developed an accessible conference website. This conference is now a global conference, a global village. However, like a homeless person, a person without a computer is excluded from our village. In the villages and communities to which you return, you have the opportunity to advocate for accessible and available buildings, products and transportation to be used for health, education and



employment.

### Advocacy for Legislation

Of course, advocacy for legislation is a very important movement activity. This conference is honored to have among those attending members of parliament. They deserve the support of advocates to assure that technology is available and accessible and that health, education, engineering and social research addresses disability problems. Here in the U.S., advocacy has brought us many pieces of legislation related to technology. Most familiar is the Americans with Disabilities and the Rehabilitation Act which established NIDRR. Both pieces of legislation carve out technology as an important means to achieve civil rights. Our country's Telecommunication Act mandates accessible equipment and the Technology Act provides support for consumers and providers to do systems change in all 50 states.

### International Activity

NIDRR is involved with disability and science and technology communities in a number of ventures in the international arena. NIDRR supports the World Institute on Disability's International Disability Exchange And Studies 2000 Project in leadership development. NIDRR and other agencies have supported travel of technical personnel to address medical, engineering and other issues. NIDRR and Japan have a common agenda in educational and assistive technology. NIDRR has long been involved with India in a spinal cord injury project. NIDRR and the National Science Foundation are supporting a Web Accessibility Project, working with the international telecommunications business community, to design an accessible Internet.

International cooperation between people and nations in assistive and educational technology is at a formative stage. The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the UN General Assembly and many states, emphasizes the importance of assistive devices for persons with disabilities. Much of the cooperation and activity seems to be concentrated in the industrialized countries.

### Personal

My commitment to a combination of community organizing and research began a long time ago. My family came to this country as immigrants and my father did not have an elementary school education. Our family learned to advocate for ourselves and to receive education. Long before I went on for a doctorate, I trained as a community organizer and teacher. I taught and worked in urban and rural communities, like Harlem in New York City and in rural Arkansas. I remember when I first began to lose my hearing. I was a very poor graduate student who could not afford technology and did not know much about hearing loss. I did find a consumer group, Self Help for Hard of Hearing. Eventually, I was on the national board of the group advocating for research and services for people who are hard of hearing or deafened. Today, thanks to a joint effort by consumers and professionals, assistive listening devices are sometimes available in places of worship, in the cinema and other public places. Television is captioned and telephones have amplification. Everyone in this audience knows how hard this work is. But the work must occur. We cannot view technology in its various forms as divorced from human values-the obscure widdits of technical people. Technology means health, nutrition, education and employment. Individuals, communities, countries and the international community must press



for the availability and accessibility of technology: technology for individuals-assistive technology- like crutches, wheelchairs, hearing aids augmentation communication devices; technology which is universally designed so that housing, products, telecommunications and transportation can be used by everyone. A good friend of mine, Irv Zola once said:

Special needs are not based on breaking the rules for the few, but on designing a flexible society for the many.

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Remarks by the U.S. Secretary of  
Health and Human Services

Donna E. Shalala is the U.S. Secretary of Health and Human  
Services.

I've haven't seen so much power in one place since Beijing -  
no, make that Hairou.

Because, the greatest learning experiences at the Beijing  
Conference and the NGO Forum didn't happen during speeches. They  
never do. They happen during conversations. They happen when  
women of different cultures and backgrounds share experiences and  
information. And, that is why we are here.

Those of you who went to the NGO Forum in Hairou will  
remember where that Women with Disabilities tent was originally  
located. It was at the very far end. In the middle of this big  
field. Exactly what it shouldn't have been: hidden.

There were no wooden planks. No curb cuts. Not to mention  
the mud created by the rain. It was where it shouldn't have  
been: totally inaccessible.

But, then something very important happened. Women from all  
over the world stood together and said enough is enough. And do  
you know what? Because of all of us, they moved that tent to the  
very front - and made it more accessible.

I tell this story for two reasons: I tell it because even  
at a conference dedicated to women's rights, it shows the extra  
mile that women with disabilities often have to travel to get  
basic fairness. And I tell this story because it shows that this  
fight will only be won when it is everyone's fight - men and  
women, non-disabled and disabled.

Because, issues affecting women with disabilities are not  
just disability issues. They're not just women's issues. They  
are challenges for every single person on this planet - every  
single person. And none of us can give up until we meet them.

As we made clear in China almost two years ago: Nations are  
only strong when women are strong. And women are only strong  
when all women are strong. When all women are healthy.

International Action Needed

Because when women with disabilities are denied access to  
fundamental rights and fundamental health care, including  
reproductive care - we need international action.

When landmines, domestic abuse, genital mutilation, and  
other forms of violence continue to tear at the lives of women  
around the globe - we need international action.

And when prejudice, ignorance, and other barriers stop women  
with disabilities from getting the nutrition, physical activity  
and other tools they need to live full and healthy lives - we  
need international action.

Far to Go





In this country, it's been seven years since we passed the historic Americans with Disabilities Act. I, like many of you, am proud of the distance we've come since then - but angered and energized by how far we still have to go.

I'm proud that we're using the court of law to vigorously enforce that ADA - and demand that every door of opportunity be kicked and kept opened. I'm proud that we have an Interagency Council on Women - which is ensuring that we turn the Platform For Action into a reality for all women. All women.

I'm proud that we've published the first ever national survey of people with disabilities - and that we're funding scientific research to better address the unique health needs of women with disabilities. I'm proud that we're fighting to ensure that disabled women who can work are able to work - and still keep their vital health benefits.

I'm proud that we're working to integrate the unique challenges faced by women with disabilities into all our health policies - from preventing teen pregnancy to promoting physical activity.

### Violations of Humanity

And, I'm proud, that we have not let our actions stop at the border. Whether it's happening to our daughters here or anywhere else in the world, we will continue to make it clear that genital mutilation is a violation of our humanity; that rape as a weapon of war is a crime against humanity; and that the trafficking of women and children for prostitution and slavery is simply inhumane.

And we will never forget that despite these victories, victory itself still eludes our grasp. Many Americans were reminded of that just last week.

### Inaccessible Doll House

It seems that the toy maker, Mattel, came out with a historic new doll. Like every Barbie Doll, Share-a-Smile Becky, was absolutely beautiful and flawless. Only instead of standing, she happened to be sitting in a hot-pink wheelchair.

Great progress, right? Well, as many of you know, there was one big problem. And it took a young girl with a disability to alert the company to it.

The problem was that this new doll with a wheelchair couldn't fit into the elevator of the \$100 dollar Barbie Dream House. In other words, while Becky could visit some other places - namely the much cheaper, one-room, doorless Traveling Surprise House - she had no access to the gem of the Barbie world, the Dream House.

As the local high school student who noticed this defect put it, "This is what we live with every day."

Clearly a case of good intentions gone awry. But, it is much more than that. It tells us that if every woman with disabilities is going to have access to good health and good health care - we need more than a little change here and there.

### Fundamental Changes

We need a fundamental change in attitude, in policy, and in policy makers. A change of the mind and the heart.

We must dream and work for the day when the issues affecting women with disabilities are not placed in a little box off to the side. A day when the research on women with disabilities is a part of all research. And when health care for women with disabilities is a part of all health care.



We must dream and work for the day when women with disabilities are not seen as one monolithic group - but rather as individuals whose experiences are shaped by their own culture and country, race and religion.

I dream of the day when people from around the world finally understand that having a disability is not the same as being sick; that women with disabilities are often very healthy. But, like all women, they need to stay healthy. And so we must promote good health and prevent secondary disabilities by helping all women to avoid tobacco and injuries - and to get proper nutrition, physical activity, and reproductive care.

Let us imagine the day when there are no longer barriers keeping women with disabilities from getting what all people deserve: health, education, family, independence, and love.

Let us fight to ensure that all health care professionals - whether they're in small clinics or large hospitals - are accessible to women with disabilities, knowledgeable about them and responsive to them.

And, let us promise that women the world over will have access to the tools they need to live fulfilling lives - from the most basic health to the most state-of-the-art technology.

### Missing Voices

But, if that is going to happen, there is something else we must do. Because every day in communities here and abroad, issues affecting women with disabilities are being debated. The deals are being brokered. And the decisions are being signed, sealed and delivered. But, too often, there is something very important missing: the voices of women with disabilities. As we said very clearly in Hairou: This must change.

We must dream and work for the day when disabled policy makers are the rule - not the exception. A day when the decision making tables of every nation will be filled with leaders like Florence Nayiga of Uganda, Maria Rantho of South Africa, Judy Huemann and Susan Daniels of the United States - filled with leaders like all of you. And a day when women with disabilities are making policy decisions at every level. About every issue - not just disability issues.

### Blueprint for Victory

We don't have all the answers - but must have the will to find them. And just like in Hairou, we are here to learn from you. To learn from each other. And to take back to our respective countries more than good friends and good ideas- we must take back a blueprint for victory. And we will. We will.

But, only if we join together - all of us. Only if we reach out to men and to non-disabled people - because this fight cannot - and should not be won without them.

Only if we do as you have always done, push forward, despite the setbacks, despite the obstacles.

And, only if we heed the words of Helen Keller, who said, "One can never creep, when one feels the impulse to soar."

With you leading the fight, I know we will soar - soar right to justice and on to victory.

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## Introduction

About fifty years ago, special education was introduced in Kenya through voluntary effort. In 1946 a special school for children with intellectual impairments was opened at St. Nicholas, now known as Jacaranda Special School. A year later, the Salvation Army opened a rehabilitation center at Thika to assist those veterans of World War II who had lost their vision during the war. Seeing that there were not many men who went to the center seeking for help, the management decided to turn it into a special school for children with visual impairments. The specialists training for teachers had to wait another 20 years before it was started, also with the help of external influence. In 1966 training for teachers of children with intellectual impairment was opened in Jacaranda Special School. However, on realizing that its graduates were not being assisted to open new programs, the training was discontinued the following year. It reopened again in 1968 and that time moved to Highridge Teachers College where it remained until 1986 when it moved to the Kenya Institute of Special Education (KISE). The training of teachers of children with hearing impairments began soon after that those with intellectual impairment. At one time it was housed at Kenyatta College then moved to Siriba then Kamwenja where it remained until KISE opened in 1986. The training of the teachers of children with visual impairments did not begin until 1980. This too was established with the help of external donations. The last specialist training program was that of the teachers of children with physical handicaps which was introduced in 1987 at KISE.

It is evidently clear that the development and growth of special education in the country has largely continued to depend on external influence and support. Both the colonial and the independent Governments appear to have not been actively involved in its planning, implementation and coordination. The result of this absence of active Government participation has led to a situation where up to the present moment special education is accessible to less than 5% of the children and youth who need it.

While accepting that the country witnessed rapid expansion of special education in the 1980's, there are still good reasons to believe more would have attained if the Government played a more active role. Dependence on foreign influence and support has made the Government spend less time examining new innovations in terms of relevance to our situations and also resources. There has also been under utilization of our own human and material resources in providing services to people with special needs.

Accessibility to opportunities be they education, health, employment and participation will not be attained unless and until disability is viewed as a developmental issue. It is treating disability as a developmental issue and integrating with all other development programs which will ensure active Government participation. Disability programs would then be given priority in all Government's development plans not left to external support. By being productive, the disabled population will then be able to participate in an equal footing with their non-handicapped members of the community.

## Enrollment Patterns and Drop-Out Rates in Special Education

Several factors tend to have an influence on the enrollment patterns in educational programs in this country. There are also some observable factors which also appear to influence the drop-out from schools among boys and girls. Most of these factors apply to both regular and special education. Disparity





in enrollment is known to exist in both general and special education and also between rural and urban as well as between sexes. While more than 90% of the non-handicapped children of school age children are enrolled in educational programs, less than 5% of those with special needs have access to education. It is also known that the enrollment rates are higher in some districts and extremely low in others. While the enrollment age is presently set at 6 years of age, it is common to find older children in some districts. It is normal to find the ten and over aged boys and girls in lower grades in Turkana, Narok, Kajiado and the North Eastern districts while such children cannot be found in parts of central, Nyanza and Western provinces. They cannot be found in nearly all the urban schools. School curricula in this country are designed with the age of children in each grade in mind. Any child, for example who might be ten years old and enrolls in Level 1 will find the curriculum was designed for 6 year olds and is meaningless and irrelevant for his/her age. Boredom will be the order of life while in school and this may lead to school drop-out. This has been observed to happen mostly three years after school enrollment. It could have happened earlier than this except that the children remain enrolled while trying to learn how to read and write. The other reason of their delay in enrollment could be attributed to the scarcity of special schools and units, and sometimes due to distance to reach the ordinary schools. This is a major problem for children with physical disabilities. Like in the case of regular education, such children find the curricular meaningless and irrelevant and soon might decide to drop out of school early.

In many traditions in this country, families tend to give priority to boys when it comes to the provision of education. In some communities, a family would be more than willing to sell a portion of land to raise money to send a boy to school than it would in case of a girl. Such beliefs would equally apply when it comes to the case of a disabled son or daughter. Another cultural factor which influences the enrollment patterns and drop-out rates in our schools is early marriages and pregnancies. The practice forces girls to drop-out from school as early as they get married secretly by their fathers to wealthy men. Lastly, but not least, poverty also plays an important role in influencing the enrollment patterns and the drop-out rates.

In order to arrest this situation, the Government has a major role to play. This is more so in the case of special education and also for girls in general. To begin with there should be some legislation to make education compulsory for all children regardless of their gender. Regular and special education should be viewed as an integral part of the country's general development, and therefore allocated enough human and material resources. Policies should be made where the burden for special education is shared between the central and local Governments. The cost sharing policy in education has made enrollment in special schools decline in recent years and the end is not in sight. A policy which compels the local authorities to provide and maintain physical facilities while the Government provides the teaching staff and learning materials will ensure services are available to children with special needs. This could also apply to regular education. In this country, a great deal of development has been achieved through the Harambee effort. With the Government support and encouragement, community-based rehabilitation (CBR) programs could have come up since the 1980s. This would have made the services accessible to more children with special needs. The 8-4-4 Education system has made it impossible for students with visual impairments to gain university entry as they used to before. Education that ignores the individual's potential leaves a lot to be desired and should be desisted.



## The Impact of the E.A.R.S. Program

Since launching in 1984, the Educational Assessment and Resource Services (EARS) has made an impact in the development and expansion of special education in this country. Realizing that there has never been an attempt to carry out a national census to establish the extent of the disability problem, data from EARS show the problem is big. By the end of 1989, over 50,000 children had been identified. Analysis done on the first 22,000 identified children shows that 59% were males and 40.7% were females. The relatively large difference between assessed boys and girls may be due to the fact that more males have handicaps compared to females which is corroborated by findings in other studies on the prevalence of handicapping conditions in children. It may also be due to cultural reasons, some communities are more interested in giving education to boys rather than girls. At that time, there were less than 20,000 children with special needs enrolled in all the country's special schools and units. The implications here are that while resources are being spent to identify children with special needs, most of them continue living without the services for intervention. The opportunity to gain the advantages of early identification and intervention cannot therefore be made.

In order to bring the services near the people, the EARS program has plans to open up workshops for the production of adaptive aids in all the provinces. Two such workshops have been opened and are operative at Nakuru and Kisumu. Three more are about to be operational at Embu, Nyeri and Kakamega. All of this is indeed positive development, but without active Government involvement, one wonders about its sustainability once the external financial support from Danida is phased out. Let us hope the Government has plans for eventual take over when that time comes. The KISE was constructed and supported by Danida and it still needs that support to meet the objectives for which it was established.

## Consequences of Integration vs. Segregated Education

From our historical point of view there is need to conceptualize integration differently from people in the developed world. A number of reasons can be advanced in support of this stand. Firstly, in our history there has never been a time when alternative living arrangement for people with disabilities is known to have existed as it did in Europe and North America. A disabled man or woman always lived with his/her family and immediate community. However, in Europe and North America institutions for such people were built away from the community. Families permitted their children to live and remain in such institutions for all their lives. At times information that the siblings had a disabled brother and/or sister was withheld. In our situation the family always felt responsible for the care and the well being of their disabled member. If there was abandonment, this only happened when the lives of the family members were in danger like in the case of invasion by an enemy. This also happened to able-bodied members who could not flee.

The opening of special schools segregated the child from his/her family for a period of time when the schools were in session. However, the child rejoined his/her family and neighborhood during the holidays. If this argument is accepted, there is reason, therefore to speculate on what type of integration should be considered as our main concerns.

One such concern for us is how we could make a child with special needs maximize his/her potential. Another concern should be that of making him/her independent and productive member of his family and the community. Lastly, but not the least is to accept and appreciate the differences between us and people with



disabilities. While we appreciate the fact that special schools in this country tend to alienate children with special needs from their family and environments, we should recognize that this also happens to non-handicapped children who study in boarding schools. For this reason, therefore our special schools cannot be viewed as segregating the children with special needs from their environments. In fact special schools expose the child with special needs to other cultures and experiences. From an educational point of view, segregated programs allow for individual attention from the teachers. This is difficult to be maintained in integrated programs due to class size, lack of learning materials and barrier - free environments which can be advanced in favor of special schools and units for children with special needs in the developing countries. However, there are children with special needs who can learn in ordinary schools successfully. Such children can be integrated, but effort should be made to equip the teacher with the needed skills and also assure him/her of assistance whenever this arises.

### Suggestions on Education for Girls with Disabilities

In our traditions, girls appear to be disadvantaged compared to boys. They have no rights to inherit the estates of their fathers. They are not considered in most tribes when sharing out family assets. While many families are more than willing to sell a piece of land to raise school fees for a son this is not so in the case of a daughter. Whenever such a need arises, the result for a daughter is to discontinue her schooling. Daughters are married in some cultures secretly too wealthy men without their consent and at times when too young. Compared to the non-handicapped girls, those with handicaps are even worse off. Many families are reluctant to spend resources on their handicapped girls, since their presence in the family is viewed with a lot of regrets. The country has had no regular primary and secondary schools for girls with handicaps. They are made to compete for places in schools for boys e.g. Thika. Disparity exists in the enrollment ratios for boys and girls in all our institutions of learning. The difference is worse in special education. Accepting there are more boys born with disabilities than girls, there still exists visible biases when providing services to the two groups.

In order to correct this imbalance, Government must come up with legislation that recognizes the right for education for all children. Education should be declared compulsory for all children. There should also be laws to punish men who sexually abuse women and more so if the woman is disabled. Fathers who marry under age girls should all be severely punished. Plans should also be made to re-enroll the girls who drop-out of schools because of pregnancies. It is wrong to allow the boys to remain in school when the girls are discontinued. In terms of vocational opportunities, the Government and society at large must stop the stereotyping of what is suitable for boys and for girls. All this can be attained when the disability would be viewed as a development issue that has to be planned and coordinated at all levels. The non-handicapped population has to accept and appreciate the differences created by disabilities. This acceptance appear to have been appreciated in other aspects of life but not in disabilities. Diversity is strength and this is not different in disabilities.

In conclusion, accessibility to education, vocational training and employment should be viewed as a right for all citizens regardless of their sexes. This can only be attainable in any country with the Government's active involvement. Laws against discrimination on the basis of gender need to be enacted for the benefit of all.

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## Holding Up Our Half of the Long White Cloud

Pauline Winter is the Chief Executive Officer of Workbridge, Inc., New Zealand.

Home is Aotearoa, land of the long white cloud, also known as New Zealand. Three million people live in New Zealand. According to our latest census, around four in ten New Zealanders have some sort of disability or long-term illness.

Workbridge is an organization which provides jobs and training for people with disabilities. We believe that given choice, given opportunity, given appropriate resources, people with disabilities can achieve both the ordinary and the remarkable.

Take Julie Campbell, who is currently studying for a Bachelor of Arts in social sciences and hopes to go on to criminology. She has scaled the second highest peak of Mount Ruapehu, one of New Zealand's highest mountains. She also was born with no arms and one leg. Julie makes the point she was equipped with an intelligent brain and good coordination with her multifunctional foot, mouth, chin and shoulders. Workbridge organized a specially adapted telephone system, a table and chair to enable Julie to do her receptionist job. She beat 119 other applicants. We just helped make the opportunity realistic.

New Zealand women have a history of pushing the boundaries. Our suffragists were the first in the world to get the vote. Today we have an internationally high ratio of women in parliament and are heading towards our first woman prime minister. We have a reputation for our pioneering spirit, some might say our stropiness.

One of our foremost writers, Katherine Mansfield spoke of having "The courage of your excess - to find the limit of yourself." And we seem to have taken it to heart.

### Workbridge Approach

Let me tell you some more about the organization I work for. Workbridge is a unique organization in New Zealand's disability sector - and indeed, the wider world. Our labor market approach means we get people with disabilities into real jobs. Not jobs in sheltered workshops, not supported jobs.

Real jobs earning real money, where the employee can develop skills and enhance self esteem.

Our goal is "To meet the aspirations of people with disabilities for full participation and equal opportunity in the labor market". Some see Workbridge as a lean, mean machine. We have caused a few hackles to rise because of our commercial approach ...

We negotiate with employers in a business-like manner, we have defined systems we work by, and we regularly benchmark our performance - just like a private sector organization.

I am viewed with suspicion by some people. Some of the comments I hear are:

- "Who do they think they are, believing people with disabilities know what they really want?"

- "Workbridge only works with the 'cream' - the easy job placements."

I make no apology. Being at the forefront of progress will always raise eyebrows. Cap-in-hand doesn't get the results we need. I accept that progress is slow for people with severe disabilities and high support needs. We are working alongside special interest agencies, and we have seen remarkable headway.

Our organization used to fit a very different mold. I'd like to



take you on a journey to show you where we've been and where we're going. You can judge for yourselves.

I make no excuses for my personal approach. I come from a private sector background. I cut my managerial teeth in the building sector before I moved to Workbridge seven years ago. That's an industry that takes no prisoners, especially in a small market like New Zealand.

It is a dramatically different environment from the old-style state sector, which has traditionally provided both funding and policy guidance to the disability sector.

### The Recent Past

Up until the 1980s, consumers of social services in New Zealand, many of whom were women, had to endure poor service and lack of choice in the closed public sector shop.

In the 80s, New Zealand went through a period of major reform. Our Rogernomics was similar to Reaganomics in the US and Thatcherism in the UK. Our dependence on the state was scrutinized. Our expectation of cradle to the grave welfare was shattered. We were dragged, protesting, to stand on our own two feet. The public sector was reduced and encouraged to become more responsive and flexible.

At the same time, Te Tiriti O Waitangi, the Treaty of Waitangi, has been upheld with renewed vigor. The 1840 Treaty is the founding document of nationhood created by British colonials and the indigenous Maori. These developments created a sea change in the minds and souls of New Zealanders.

Funding for welfare services were splintered and competition for our slice of the pie forced us to re-examine the services we provided and how we provided them. We were well and truly shunted out of our comfort zone. We had to emerge from our bureaucratic role and take on new roles. We became brokers, mentors, instructors and a true employment placement service.

### The Present

Getting back to the idea of customer service, we recognize that each of our jobseekers and employers want and need different situations and skills. It is a given in the building industry, as it is in retail, manufacturing - you name it - consumers want variety to suit their diversity. It's up to the service provider to provide an array of goods at an appropriate time, so the consumer can decide what they want and when they want it. So people have the right to choose where they work. People with disabilities have the right to participate fully in their communities. This is a quantum leap away from the attitude of 'us doing something to them'.

Now, as Workbridge Inc., we work in partnership with jobseekers and employers to come up with appropriate solutions. We provide support around opportunities in the labor market. That support is individualized and flexible - for both the job seeker and the employer. We have 27 community-based employment centers throughout New Zealand, each employing a team leader and up to four placement coordinators.

Last year, we placed more than 3500 jobseekers in jobs, and almost 5500 into training opportunities. We have around 55,000 jobseekers on our books, which is a lot in a country of three million.

Our clients have all sorts of disabilities from very minor to severe, from amputations to depression. Their skills and education are diverse. Some are tradespeople, some have degrees, many have little formal education. Take Fiona Smith, for example. She lost all sight in her left eye through multiple sclerosis. But, as she says, she didn't lose her vision. She had to leave her pharmaceutical sales job. Workbridge helped her start her own



business: Absolutely Active. Fiona is an adventure activities broker - she finds clients for recreation companies. Adventures include everything from rafting and rock climbing to fishing and sailing. She only started sailing a year ago and now has her day skipper's and competent crew certificates, a radio operator's license and a coastguard boatmaster qualification.

## Women and Workbridge

Our Workbridge Women component acknowledges that women with disabilities face special barriers when trying to enter the workforce. All the traditional hurdles for women plus some. They have lower levels of education and skills, opportunities and career choices are more restricted, self-esteem is often low, and there are few female role models.

In 1992 a government report showed that women with disabilities had one of the highest unemployment rates of any group in New Zealand. By acknowledging those barriers and the different needs of women, we can assist them on the road to economic freedom. To do so, we had to look hard at ourselves.

Women weren't extensively using Workbridge's services. Only 38 per cent of those on our books were women. We developed a four pronged approach to change the situation.

? This included the Workbridge Women's Week. This is an annual event designed to increase the profile of women with disabilities who were seeking employment.

? The Workbridge Women's Study Awards are an annual scholarship open to women with disabilities towards training. We have awarded grants for women to take computer courses, teacher training, chef studies, occupational therapy, art and design, PhDs - the training opportunities are as varied as the women registered with Workbridge.

? We have appointed "Wanda Women" on each team to keep team members focused on the issues facing Workbridge's female customers and to organize workshops.

? Then we have the Workbridge Women's Workshop, a four day seminar created to move women jobseekers closer to their vocational goals. It involves self awareness modules, and presentation skills, job search, networking and so on.

As a result of the four-pronged women's program, enrollment of women jobseekers jumped from 38 per cent to half of all Workbridge jobseekers and women in training.

More significantly, we have seen a jump in the number of women with disabilities getting jobs.

## Other Specialized Outreach

Likewise, we developed specific services to cater for Maori people, the indigenous people of New Zealand. Maori people have a high incidence of disability. That's for a variety of reasons relating to our colonial past, access to healthcare, and economic status. They have quite a different view of disability, and have different values and structures than the dominant western structure of service delivery.

? We have also developed programs that cater to the needs of Pacific Island jobseekers, which again has produced great results.

? Our other main group of customers is the employers who provide the opportunities to our job seekers. We have products for employers to suit their industries and employment needs. We have also started an Account Management system, where we develop a close relationship with a large employer, one which generates repeat business and provides a wide range of opportunities for people with disabilities. This has been pioneered with one of New Zealand's largest employers -





McDonald's. From McDonald's point of view, by using us they reduce staff turnover, get pre-screened and prepared employees, and support is provided by us as needed.

? We also administer the "training support" fund which covers costs during work experience, training or education; and "Self Start" funds which helps people set up their own business ventures.

#### Radical Changes

The environment in New Zealand has changed radically in a short time. Human rights and equal opportunities legislation was a long time coming and is to be celebrated. These changes have been the catalyst for developing new services. One of our recent milestones was getting our funding moved from the social welfare department to labor - where we believe it belongs.

I'd like to close with another quote from one of New Zealand's wise women, Katherine Mansfield:

"Risk!

Risk Anything!

Care not for the thoughts of others

Do the hardest thing on this earth."

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## Organizational Development of Disabled People in Russia

Tamara Zolotzeva, Vice-Chairman of the All-Russian Society of Disabled People

The All-Russian Society of Disabled People (ARSDP) is a public, non-governmental organization, that was founded in August, 1988 due to the active movement of people with disabilities. It operates in accordance with the Constitution of the Russian Federation, legislation and ARSDP regulations.

During the last nine years the ARSDP has become the largest, powerful and authoritative public organization, which unites about 2.5 million disabled persons.

The ARSDP has a distinct structure, involving 78 regional organizations, acting on the whole territory of Russia on the basis of their own Constitutions. The regional organizations are based on the work of 2,184 local and 25,000 associated organizations.

The activity of the ARSDP is directed towards the representation and protection of the interests of the disabled and creation of equal conditions and possibilities, promoting the integration of disabled people in the society.

The highest body of the ARSDP is the Congress. It evaluates the work done and adopts a Program of Action for the 5 year period.

The Central Board ensures the work of the Society during the Congresses. It is represented by disabled people themselves. It has its Meetings once a year. The Presidium of the Central Board (20 people) deals with the items of the current business of the Society during the Meetings. The Central Board has created the special Body (of hired staff) which ensures its work and connections with regional organizations.

The structure of the ARSDP includes different functional subdivisions uniting members according to their interests, for example, recreation and sport, women and youth clubs, clubs of the parents of disabled children, of wheelchair users.

The main financial source of the ARSDP is its own business activity, supported by the state in the form of the reduced taxes. There are about 1,700 enterprises run by the ARSDP. Their



main task is employment (creation of the working places) for disabled people and financing of social program of the group . Our organization finances Art festivals, sport and recreation events, development of tourist and leisure activity, work of small centers of rehabilitation, help in repair and equipment of accessibility in apartments, acquisition of medicine and wheelchairs. It also helps disabled people of the rural area in delivery of fuel and foodstuffs.

Our main achievement is the establishment of the close business contacts at all levels of authority. It gives the opportunity to conduct governmental decisions not infringing the interests of disabled people, to create the policy towards themselves taking into account the opinion of our society.

One recent result of this work is the adoption of the Law on Social Protection of People with Disabilities in 1995 and the creation of the Committee on Disability at the level of the President's Council.

Besides that the representatives of our organization are included in a number of governmental commissions (on social reforms, for example).

The ARSDP informs regularly the members and the society about its activity. Nowadays 16 newspapers and 4 journals for disabled people are published, with the issue of about 200 000 copies.

The main direction of work, determined by the Program of the activity of the ARSDP 1996-2001, is the promotion and realization of the Law on disability through the legal and legislative basis, developed system of rehabilitation and free access of disabled people to information.

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### Encouraging Women Through CBR

Carmen Reyes-Zubiaga of the Philippines, is currently the acting Executive Director of the National Center for Disabled Persons, Phnom Penh, Cambodia.

In our region, the majority of women with disabilities are experiencing double marginalization. One is because of having disability and the other is because of being a woman who cannot perform the task expected by society of every woman. Others have taken their disabilities as misfortune while a few struggle to be recognized as a person apart from having disabilities. The women who are here today belong to the chosen few.

As a woman with disability myself, I believe that like any other great men and women, we too can change a part of the world where we are and we are capable of making life a little different for other people with disabilities.

My first encounter with the CBR concept was negative. I questioned the possibility of rehabilitating people with disabilities right in their own communities and achieving self-reliance as they live together with families. Why? I was looking at my own experience. Being with my family for twenty four years never gave me the drive to change my life. I only started to strive harder seeing many disabled people in a center who were in a worse condition than me and striving hard in spite of that. I was challenged so I found my way out from my sleepy town and found life easier in a dormitory for students with disabilities. I studied in a regular school, lived away from my parents for seven years and I learned to live independently in a not so accessible environment. Would I have finished my university degree and found job if I stayed in my community? No way! And maybe, I would not have had the chance to marry and have children because my family had already instilled in my being that they would take care of me forever.



I had lots of questions such as the commitment of volunteers; what processes will take place for the community to adopt CBR as their own project; how will disabled people be reached and what roles will they play. During my early years in disability circles, I always thought that CBR Programs shown to foreign visitors as successful models were just shows. And they often really are! Showing only one aspect of rehabilitation in a community, usually medical models training volunteers to become therapists looked silly to me. For how long will they do that? And who trains them to do CBR? Most of them are foreigners and professionals who come to the village in shiny limousines and high heeled shoes. And they were teaching farmers and fish vendors to do PT or fill out a monitor sheet. Isn't that funny?

### Realization

As I became committed to my work and to improve the lives of people with disabilities in the center where I worked as Development Officer, I began to see the flaws of center based services. I developed projects based on the needs of people with disabilities for employment and after training support which were all center based. There were always pressures to look for more funding because of the growing administration cost and maintenance of the big building. Fund raising here, selling raffle tickets there, writing proposals and so on. But as time went on, I began to pose a lot of questions with the results of my work. I felt that there is something missing. There was a big gap which I could not identify where. I also felt that the center's philosophy to train disabled persons in the center and bring them back to their respective community sounded silly. I thought that they never realized how hard it would for a disabled person who have experienced self-reliance in daily living, to go back to their places without any support. Inaccessible roads, house not adapted for wheelchair, and job hunting in a place where the skills they learned were irrelevant.

I also began to hate these funding agencies who wanted to have a number of beneficiaries, but would never support salaries of staff. There were also some instances when disabled people came but were rejected by the center because their category does not fall within the target clientele of the organization. I took a one year study leave to get my master's degree.

After two years, I did not expect that I would come back to the same town where I visited during the CBR training I attended. I was then a part of the team doing area assessment as a part of the group thesis we had to present in our master's class. I happened to interview a former CBR volunteer who remembered me. She related to me the sad ending of the CBR Program which was claimed to be successful. She requested me to meet with a group of people with disabilities from that town. I could not say no and following day, I was in front of five men on crutches and one lady who was hunchback. All of them were relating their disappointment about the promised help from the government to lend them capital for small business. I just listened and later, pacified them that we shall try to find solutions to their problems. I was bothered after that situation. It was a living proof of the condition of people with disabilities in the rural area, not so far from the capital city, where all the facilities and support for disabled people are concentrated.

I started to think about the CBR Program. It may not be a perfect approach but somehow it had changed the lives of some disabled people in the community. They have now the link themselves with the government, they are now aware and can express their needs and most important is that they had met with other people with disabilities within their communities to discuss their problems. CBR seemed to be good but there are some loopholes that need to be filled to achieve the goal of





providing services to people with disabilities within their community.

I promised to do CBR, but based on a strong foundation made by people with disabilities themselves.

#### The Rizal CBR Program: Looking Back

AIDAB approved funding for the initial stage, which was focused on community organizing, volunteers' orientation and training of people with disabilities as leaders and in managing small businesses. The Rizal province has a population of 1.2 M. It is composed of fourteen municipalities which were both rural and urban in character. The eastern part is composed of six agricultural towns while the southwestern part is fast becoming industrialized because of its short distance from Metro Manila. The province is often a destination for local and international tourists but because of traffic and underdeveloped roads, other potential tourist spots were not yet explored. Politics is very strong as in any other province so that dealings with government and other group leaders should be done with utmost care.

The entry point for each town was through the Social Welfare Department which also handles disability programs and services. Often, the response was not encouraging so we had to go straight to the mayor of the town. Because it was timely for election preparation, the response was really overwhelming. They even volunteered to coordinate meetings with the village chief, women leaders and people with disabilities who were active or willing to listen about the program. As the first person with disability to talk about helping disabled people in their community, I enjoyed support from the local government officials, civic leaders and women volunteers. The center I worked with is also popular and established credibility in establishing income generating projects for the disabled, a strong factor that influenced the success in gaining community support. In six months, our CBR Team, composed of three members, organized Volunteer Core Group in eleven municipalities. Our first Volunteer's Assembly was attended by about a hundred volunteers from 12 municipalities. The next steps was to organize the CBR Task Force composed of representatives from government agencies and non-government organization working within the province. The purpose of this group is to establish relationships and encourage them to include disability issues within their programs. This is also to show to the community groups that there is support from the provincial level. The Task force developed a survey form that the volunteers used in identifying people with disabilities. The Task Force was also involved and spearheaded some information campaign about disability. One remarkable example was the pilot survey in one village with 5000 population that identified about 120 persons with disabilities. The survey was done by village officials, CBR volunteers and members of other NGOs. It was the first time that such collaboration happened and government funds were used for this purpose. Then, surveys in all towns were carried out by volunteers and village officials. In a period of three months, about 1300 people with various disabilities were identified.

#### Taking the Lead

The striking characteristic of our CBR Volunteer Group was that people with disabilities were members and were encouraged to take the lead. The volunteers were trained to give support to community leaders with disabilities. The goal of the CBR Volunteer Group was to organize a group of people with disabilities from their municipality to advocate for the local government to include disability programs in their plan. Community Volunteers were mostly women from thirty-five to



fifty-five years old. Most of them had a relative with disabilities. What was interesting was that, I encouraged former volunteers from the fallen program to join again and share their experiences with other new volunteers. Being a person with disability was an advantage because I could easily get their sympathy and I always cited myself as an example of what could result if they would help a disabled person to improve their lives. Through them, disabled people from the community surfaced. As expected, they were not aware of what is going on in the community because they were confined in their small corners. They have no idea of what's awaiting them and that given the chance they can become contributing members of their communities. After identification of potential leaders, a series of personality development seminars were conducted in 14 municipalities. It was followed by an introduction to organization and planning exercise.

#### New Council Established

Nine out of eleven municipalities were able to organize self-help groups of disabled people and register them to the Securities and Exchange Commission. After organizing the nine municipalities, a provincial seminar for leaders was conducted which led to the formation of the Rizal Council of Persons With Disabilities. The council is an umbrella organization of all municipal organization and was envisioned to make representation to the provincial government. The council was also tasked to conduct community awareness campaigns and raise funds for the municipal organization. With the formation of the council, the House With No Steps, after two years, became one of the members of the council. After two years, I was not anymore the only person with disability talking with the mayors and other government officials, but instead each municipality has its representative with disability. The community organizations of people with disabilities, supported by CBR volunteers became strong groups. Because each organization was recognized by its municipal government and has national registration, they were capable of getting funds from the government and non-government funding agencies. Five municipal organizations were able to secure funds to run a credit program for people with disabilities. Other services such as medical/ physical were link with government agencies and existing NGOs. A CBR center which serves as a meeting place and information center was provided by each municipal government.

The House With No Steps CBR was so popular that medical schools began sending their interns in Physiotherapy and Occupational Therapy for one month practicum. It means that we have about 40 field workers who are training community health volunteers in physiotherapy and at the same time, administering minor treatment to persons with disabilities in their communities. The student therapist were given orientation in motivating people with disabilities and their families.

#### Case Studies of Women

Magdalena

- \* disabled woman
- \* an orphan
- \* battered wife
- \* tortured mother
- \* former prisoner
- \* How does CBR make her a whole person?

She was a fifty-three year old lady. Lean, with sad teary-eyes and a smile that hides bitterness about her past. People in her



community knew her but she seldom talked to neighbors nor joined in any gathering. Cely, one of the CBR Volunteers in Niugan had been talking to her about CBR in their town that is being supported by the mayor. In a seminar for entrepreneurship, she was encouraged to join. On the first day, she was just a quiet observer but the facilitators had their way of winning her confidence. In a casual informal forum of women with disabilities and volunteers, she began to tell her stories, which she said was for the first time.

Magda was born with mild cerebral palsy which affected the right hemisphere of her body. Her mother died from giving birth to her. She was hated by her father so her auntie took her and brought her up together with her six cousins. They were good to her but when she was 14, a man took her by force and hid her in a faraway province to be his wife. She experienced maltreatment from her husband who was a drunkard and was very cruel to her and her children. In one of his drinking sprees, he killed a townmate, so the family fled back to Manila. Magda was warned not to see her relatives under threat of death. They lived in a squatter's area. Magda was forced to work because her children had nothing to eat. They scrounged at the garbage and sell whatever sellable they could find or wash clothes for neighbors for little money or rice. Luckily, one of Magda's clients in washing clothes offered her and her husband to live on their land not so far away from Manila. They agreed and came to the town of Pililla and guarded a big piece of land with lots of fruit trees. They were also given little money and rice in exchange of cleaning and watching the fruit trees. There, Magda hoped that her husband would change but she was wrong. He became even worse. One night, he came home drunk and beat all the sleeping children. The youngest was one year old. Magda ran down the wooden stairs but her husband chased her and she was beaten black and blue. She could not bear any longer seeing her children crying with blood on their faces and bruised. She ran to the kitchen and took the big knife. Her mind became blank that she only saw the image of her husband as a wild dog that needed to be destroyed. Magda came back to her senses in front of the police station where she was handing down the bloody knife to the police. She was wrapped in a blanket and accompanied by some of her good neighbors. She was brought to the Correctional for Women. Her children had to go to the orphanage because they were minors. She stayed in prison for one year but she was acquitted because her neighbors testified that she only defended herself and her children.

After the sharing, Magda felt light and with the understanding she had from the group, she felt that she had more confident now in facing people. For so long, she had kept these feelings of isolation, guilt and anger all by herself. Magda became a committed volunteer and works against domestic violence against women and disabled people. She became an effective counselor for other women and disabled people. She even has the confidence to tell women, disabled and non-disabled, to protect their dignity as a person. Her children, who are all grown up and love her so much, were really happy to see their mother involved in community activities, sharing her story and acknowledging the support they had given her during those times when she felt like an outcast.

CBR has made her a whole person again and it was not too late to bring back her confidence to live a happier life with her children and grand children.

Precila

- \* became disabled at the height of her career
- \* from a rich family
- \* with supportive husband and children





## How Can CBR Make Her Life Meaningful?

Barangay Cogeo, one of villages in Antipolo Rizal used to be a resettlement area for squatters who were moved by the infrastructure development that took place in Manila during the Marcos regime in 1978. From a muddy, stony grassland which used to be a "salvaging" area for political oppositionists and other "bad elements", the place had transformed into a fast developing area filled with commercial establishments, new roads, subdivisions and a melting pot of people coming from different provinces of the Philippines.

Precy had witnessed all these changes and in fact, she considered herself as a victim of this development. She was hit by a six wheel truck that carried sands and gravel. She almost lost her life and was left with a disability which for quite a long time, made her felt hopeless and bitter. She was a government employee and had also struggled to go back to her job after that accident. With her children's support she was able to recover and slowly returned to her usual jolly mood. She became an active officer of the homeowners association, a member of the village advisory board, member of the church pastoral council and other activities in the village with over 200,000 population. When the CBR Team visited their village hall and explained about helping disabled people to help themselves within their community, that was the only time she thought about her own disability. She has been active in their community but she admitted she was not totally satisfied with her work. The lady village captain had invited her to the meeting because she believed that Precy could be a great help for the project. Precy was really interested in how to help disabled people in her community. She consider herself lucky because she enjoys good life and looks forward to a secured condition upon her retirement. She had never heard of CBR nor about any other terminologies in development. She works as a finance assistant in one of the government agencies. She became my constant visitor and always present at every meeting. She is always ready to go with me in other towns where we have CBR meetings and from these trips, she would pick up some ideas which she shared with her group in Cogeo. One day she phoned me and requested that we should visit a house of an active lawyer in her area. She had a feeling that he could help in establishing a community group. The result became history for the whole Rizal CBR Project. The lawyer we visited indeed fulfilled her expectation. This man, Atty. Ernesto Duran, was born with a tumor in his spine and made his way to a successful career using his walker. He does not know anything about disability issues but upon encouragement from Precy, they became partners in helping disabled people and organized a strong group.

During the provincial seminar for all municipal organizations of disabled persons organized by our CBR Program, the need to come up with an umbrella organization to support the community groups was emphasized by the community leaders and volunteers. The Rizal Council of Person with Disabilities was then organized during that two day seminar. Atty. Duran became the President of Rizal Council of Persons With Disabilities and has made several representations and recommendations to the provincial government. He is also the first disabled person to be elected as Sectoral Representative to the Regional Development Council. Being a person with disability in good status, he became a credible leader which also put Rizal Council at the helm. And guess who was very happy and proud about this? Of course, Precy. "I may not be able to lead our community group but I am proud to find somebody who could do make things happen and lead us. I am willing to support him and encourage other people to support his vision as a leader".

Achievements of Rizal CBR Project





- \* Organized community based group Headed by people with disabilities;
- \* Inclusion of disabled people in community based health services;
- \* Umbrella organizations that support CBR groups in advocacy and service development;
- \* Sectoral representation of disabled people at the local and regional council which is now being replicated by other provincial governments;
- \* Implementation of a provincial sports activity (42 km wheelchair marathon) which became a national sport activity supported by the Philippine government through the Philippine Sports Commission;.
- \* Active involvement of people with disabilities in program development and advocacy.

#### Conclusion

Community based Rehabilitation will only become sustainable if its roots are based on a strong foundation. The foundation of a strong CBR Program is the commitment of leaders with disabilities. Often, women play an important role in establishing this commitment.

#### Recommendation to All CBR Implementers and Women Leaders

Women should:

- ? insist that they should always take active roles in community based programs, especially on programs concerning disability;
- ? take time to educate women, disabled or non-disabled about us, and what we can do for our community
- ? stop portraying women as beneficiaries of programs but rather as partners that need support to contribute
- ? create a venue where women can express their ideas and share experiences
- ? help a potential woman leader to grow and use her potentials to the fullest for benefit of non-leaders
- ? use our natural charm as women to achieve our goal.

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## RESOURCES

### Fact Sheet: Women & Disability

This FACT SHEET was prepared by Rehabilitation International and the World Institute on Disability in July, 1995, for use of delegates to the UN 4th World Conference on Women and associated NGO Forum. Updated in 1997, its purpose is to provide basic facts and data about the situation of women and girls with disabilities worldwide. For further information contact any of the Forum organizers: Rehabilitation International, 25 East 21 Street, New York, NY 10010 USA, Fax: (212) 505-0871; or World Institute on Disability, 510 16th Street, Suite 100, Oakland, CA, 94612 USA, Fax: (510) 763-4109; Mobility International USA, P.O. Box 10767, Eugene, Oregon 97440 USA, Fax: 541-343-6812.

### Survival

In some countries disabled females have a higher excessive mortality rate than do disabled males. For example, although polio strikes females and males equally, research in one country recorded more than twice the number of boys with effects of polio

THE UNITED STATES OF AMERICA

THIS IS TO CERTIFY THAT the following is a true and correct copy of the original as the same appears in the records of the Department of the Interior, Bureau of Land Management, at Washington, D. C., this 1st day of January, 1900.

Special Agent

IN WITNESS WHEREOF, the Special Agent has hereunto set his hand and the seal of the Department of the Interior, at Washington, D. C., this 1st day of January, 1900.

than girls. The one explanation is that boys survived polio twice as often. (Prejudice & Dignity, United Nations Development Program, 1992 p. 33). This study supports the common observation in many developing countries that family response to sickness or disability among male children is much more serious, resulting in more visits to medical and health services. Additionally, when combined with traditional practices of males being fed before females, and female children receiving what is left over, the result is that often the disabled female child becomes malnourished as well. In this manner, diseases and disabilities which can be survived by boys, become life-threatening to girls. In countries where "son preference" is culturally dominant, girls, and especially girls with disabilities, are particularly endangered. Action is needed to help disabled girls survive and obtain a better quality of life.

## Armed Conflicts

The armed conflicts of the past decade have created more than 30 million (1989 numbers) refugees and displaced persons and the vast majority of these, approximately 80%, are women and children. (Population at Risk: Disabled, War-Injured and Refugee Children, RI 1992 World Congress Proceedings, p. 266). At the beginning of this century, only about 5% of casualties of wars and conflicts were civilians. As the century closes, more than 80% of those killed or disabled by armed conflict are civilians, many of whom are women and children. (The State of the World's Children, 1994, UNICEF, p.4). In other words, those who have the least influence on the conduct of armed conflict are now its most frequent victims.

## Landmines

Current UN estimates are that landmines kill at least 35,000 civilians each year and disable, blind or injure thousands more. Children and women are sustaining lifelong disabling injuries, including orthopedic trauma, emotional trauma, spinal cord and brain injuries, and loss of vision, hearing and mental capacity due to landmines, bombing and other explosives. (RI/UNICEF Study of the Effect of Armed Conflict on Women and Children, 1991). They are in immediate need of rehabilitation services, including technical aids and appropriate technology, yet are last in line to receive them. Their needs wait until injured soldiers and other men are aided.

According to UNICEF, of the estimated 2000 people killed or injured by landmines every month, 30-40% are children.

The social needs of injured women and girls may be as significant, according to a recent UNICEF workshop on "Women, Children & Landmines" held in June, 1995 in Cambodia. There, women gave testimony as to how their disabilities had ended their marriages, isolated them from their families and communities, and destroyed their futures. Girls recounted how they were no longer regarded as future wives or mothers, but were instead hidden away from society. They need assistance to rejoin their communities.

## Literacy and Education

Women make up more than 65% of the world's illiterate-about 600 million women do not know how to read or write. (World of Work, ILO May/June, 1995, p.4). In Africa, this percentage rises to 85%. (Women and Disability, UN Non-Governmental Liaison Service, 1991, p. 31). Recent UNESCO studies have suggested that



only approximately 1-2% of disabled children in developing countries receive any education, and it is well-known from field studies that disabled boys attend schools much more frequently than disabled girls. These studies are confirmed by presentations made to the UN Experts Seminar on Women and Disability (Vienna 1990), that in many countries it is still the norm that a girl with a disability will be hidden at home.

A 1994 conference on "Blind Women in Africa" presented information from 32 countries, demonstrating that access to literacy programs and education was often their only way to avoid a life of begging in the streets for survival. (World Blind Union, July 94-March 95, pp. 66-69).

According to research in Kenya (J. Sinyo, 1997), while more than 90% of non-disabled children of school age are enrolled in educational programs, less than 5% of those with special needs have access to education.

#### Employment

The belief that girls, and, therefore, girls with disabilities, will not benefit from education, predates women's participation in the labor force. According to the ILO (World of Work, *ibid*, p. 4) in the space of this last decade, women's participation rates in the labor force have greatly increased, both in the developing as well as in the industrialized world. However, the majority of women with disabilities have not benefited from these gains by women in general. Awareness that educating girls with disabilities can and does lead to their participation in the community including work, needs to be intensified.

A 1992 New Zealand government report revealed that women with disabilities had the highest unemployment of any group in the country.

A 1996 European Conference on Women with Disabilities (Germany, August) received reports from 20 countries. A major emphasis was on the grim situation of disabled women in the labor market, ranging from a European Parliament estimate that only 20% are in the labor force to a British estimate that one-third are employed in that country.

A 1996 Rehabilitation International/World Institute on Disability Seminar (New Zealand, September) was held on the growing phenomenon of small business development by disabled entrepreneurs, evident in Africa, Asia and Latin America. It was reported that disabled women are demonstrating a strong rate of success in self-employment, sometimes surpassing that of disabled men. A 1997 international workshop on Wheelchair Building (Kenya, January), included a group of women trainees from Uganda and Kenya who are now planning to establish production units to build appropriate wheelchairs.

A survey in the Philippines revealed that only 19% of disabled women were employed (Messell, ILO 1997) and 95% of those were earning wages substantially below the poverty threshold.

The need for access to microcredit was the strongest priority identified by the disabled women participating in the Women's Institute on Leadership and Disability held in 1997 by Mobility International USA.

#### Economic and Cultural Status

Regardless of country or culture, from the least developed to the most highly developed nations, disabled women are employed at rates far lower than disabled men. The pattern is established early on and is similar from country to country: as girls they have less access to education; as adolescents, they have fewer chances to socialize or receive guidance about planning their futures; and as adults they have fewer chances to receive rehabilitation services, enter training programs or the labor





market.

Additionally, unlike other women, they have little chance to enter a marriage or inherit property which can offer a form of economic security. Studies also show that if women are disabled after marriage, the relationship frequently ends in abandonment and divorce. (Studies include: Vocational Rehabilitation of Disabled Women in the European Community, 1988; Vocational Rehabilitation of Women with Disabilities, I.D., 1988; Women with Disabilities, the Economics of Double Jeopardy, RI, 1992, World Congress Proceedings).

**Socio-Cultural Status:** For women in any society, having a disability signifies dependency, weakness, loss of status and relegation to an unproductive, asexual role in the community. Any girl or woman with a disability who chooses to fight this demeaning stereotype and take part in her community and society has an uphill, lonely battle. Studies have shown that the disabled women who do manage to break through the walls of prejudice and discrimination usually have benefited from strong role models and/or support groups of their peers. (Pride against Prejudice, 1991, London and Resource Kits on Disabled Women, Disability Awareness in Action, 1997, London).

### Bioethics and Reproductive Issues

In many countries there are now legislative and policy pressures to prevent the birth of disabled children, to deny disabled women their right to bear children and to encourage euthanasia as a socially-sanctified "option" for people with substantial or progressive disabilities.

Around the world, disabled women are subjected to involuntary sterilization, pressured to or required to seek abortions and denied appropriate health care and assistance during pregnancy and childbirth. (European Conference on Disabled Women, IDEAS Portfolio 1997).

The right to maternity and parenthood from disabled women is now beginning to be recognized in some cultures but still opposed by many. (UNICEF/RI, One in Ten, Volume 17, 1997).

### Violence and Abuse

Physical and sexual violence against disabled girls and women occurs at alarming rates within families, in institutions, and throughout society. In many countries, disabled children are abused at a higher incidence than non-disabled children. Frequently the abuser or perpetrator is trusted by the family or a caretaker on whom the girl is dependent.

Disabled women's groups are beginning to address this issue through self-defense courses and political pressure for studies of the situation, and lobbying for inclusion of disabled women within shelters and other services for abused women.

In some cultures it is still taboo for women to publicly discuss or officially report abuse and domestic violence and, therefore, the magnitude of the situation worldwide is just coming to light (A Fire in the House, UNICEF Cambodia, 1996).

A form of violence against women that is creating disability is female genital mutilation (FGM) which can cause infertility, sexual dysfunction and serious ongoing medical conditions. Although beginning to be outlawed in some countries, FGM continues to threaten millions of women and was identified in 1997 as a priority for action by the World Health Organization and UNICEF.

A 1997 Inter-American Development Bank study showed a relationship between domestic violence and loss in national productivity. The Girlchild



Recent research has established that the first three years and, certainly the first five years of a child's life, are crucial to both her cognitive and emotional development. Specifically, the more children are spoken to and read to in a nurturing environment, the more they respond and develop.

Conversely, studies of institutionalization have shown that isolation and lack of stimulation can stunt and negatively impact a child's development. In many countries, the girlchild with a disability is given the least attention and nurturing in the family, and is often isolated from social interaction. It is of critical importance that early stimulation and intervention programs be made available to girlchildren with disabilities. As they mature, they can benefit greatly from contact with disabled women who can act as role models.

Some disability experts believe that the role model and mentoring experience is even more critical to the development of confidence and self-esteem by girls with disabilities, as they are uniformly isolated from social interaction.

### Networking

Studies and conferences on how to improve the situation of disadvantaged groups conclude that strong networks of people in similar situations can reinforce each other's confidence, draw concrete lessons from the exchange of experiences and progress further and faster through joint action. Several national and regional networks of women with disabilities and their allies have been initiated during the 1990's but are in great need of financial and technical support to make a difference.

Similarly, networks and outreach programs to improve the situation of women around the world are beginning to include disabled women but these linkages are weak and need to be strengthened. (Loud, Proud and Passionate: Including Women with Disabilities in International Development Programs, Mobility International USA, 1997).

### Mass Media

Images of disabled girls and women in the mass media (e.g. newspapers, radio, television, film) are universally negative or absent. If portrayed in a fictional or dramatic work, they are often utilized to represent a negative situation or character flaw (weakness, passivity, evil, sickness). If reported in a news or feature story, the disabled girl or woman is usually singled out as an object of pity or charity, or conversely, as a heroine for achieving the ordinary.

Missing in the media are the everyday stories about girls and women with disabilities who are attending schools, participating in active family life, holding down jobs - part of the foreground and background of the rhythm and dynamics of communities all over the world.

### Personal Assistance and Caregiving

The world over, responsibility for care of people with disabilities, from infancy to aging parents, is overwhelmingly consigned to women. The Alternative Copenhagen Declaration (1995 World Summit on Social Development) called for men to begin sharing the responsibility for assistance needed by children and adults with disabilities.



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## RESOURCES

Extracts from Beijing Declaration & Platform for Action: United Nations Fourth World Conference on Women

This document was prepared by Anneli Jonen (Disabled Peoples International) and Kicki Nordström (World Blind Union), both from Sweden. These extracts, 38 Articles in total, provide full text of all special references to women and girls with disabilities.

### Beijing Declaration

(We, the Governments,....

3. Determined to advance the goals of equality, development and peace for all women everywhere in the interest of all humanity,

We are determined to....

32. Intensify efforts to ensure equal enjoyment of all human rights and fundamental freedoms for all women and girls who face multiple barriers to their empowerment and advancement because of such factors as their race, age, language, ethnicity, culture, religion, or disability, or because they are indigenous people;

Platform for Action  
(361 Articles in total)

### Chapter I MISSION STATEMENT (para 1-5)

### Chapter II GLOBAL FRAMEWORK (para 6-40)

37. According to World Health Organization (WHO) estimates, by the beginning of 1995 the number of cumulative cases of acquired immunodeficiency syndrome (AIDS) was 4.5 million. An estimated 19.5 million men, women and children have been infected with the human immunodeficiency virus (HIV) since it was first diagnosed and it is projected that another 20 million will be infected by the end of the decade. Among new cases, women are twice as likely to be infected as men. In the early stage of the AIDS pandemic, women were not infected in large numbers; however, about 8 million women are now infected. Young women and adolescents are particularly vulnerable. It is estimated that by the year 2000 more than 13 million women will be infected and 4 million women will have died from AIDS-related conditions. In addition, about 250 million new cases of sexually transmitted diseases are estimated to occur every year. The rate of transmission of sexually transmitted diseases, including HIV/AIDS, is increasing at an alarming rate among women and girls, especially in developing countries.

39. The girl child of today is the woman of tomorrow. The skills, ideas and energy of the girl child are vital for full attainment of the goals of equality, development and peace. For the girl child to develop her full potential she needs to be nurtured in an enabling environment, where her spiritual, intellectual and material needs for survival, protection and development are met and her equal rights safeguarded. If women are to be equal partners with men, in every aspect of life and





development, now is the time to recognize the human dignity and worth of the girl child and to ensure the full enjoyment of her human rights and fundamental freedoms, including the rights assured by the Convention on the Rights of the Child, universal ratification of which is strongly urged. Yet there exists worldwide evidence that discrimination and violence against girls begin at the earliest stages of life and continue unabated throughout their lives. They often have less access to nutrition, physical and mental health care and education and enjoy fewer rights, opportunities and benefits of childhood and adolescence than do boys. They are often subjected to various forms of sexual and economic exploitation, paedophilia, forced prostitution and possibly the sale of their organs and tissues, violence and harmful practices such as female infanticide and prenatal sex selection, incest, female genital mutilation and early marriage, including child marriage.

### Chapter III CRITICAL AREAS OF CONCERN (para 41-44)

### Chapter IV STRATEGIC OBJECTIVES AND ACTIONS (para 45-285)

46. The Platform for Action recognizes that women face barriers to full equality and advancement because of such factors as their race, age, language, ethnicity, culture, religion or disability, because they are indigenous women or because of other status. Many women encounter specific obstacles related to their family status, particularly as single parents; and to their socio-economic status, including their living conditions in rural, isolated or impoverished areas. Additional barriers also exist for refugee women, other displaced women, including internally displaced women as well as for immigrant women and migrant women, including women migrant workers. Many women are also particularly affected by environmental disasters, serious and infectious diseases and various forms of violence against women.

#### A. Women and poverty (para 47-68)

A 1. Review, adopt and maintain macroeconomic policies and development strategies that address the needs and efforts of women in poverty

#### Actions to be taken

60. By national and international non-governmental organizations and women's groups:

(a) All parties involved in the development process, including academic institutions, non-governmental organizations and grass-roots and women's groups, mobilize to improve the effectiveness of anti-poverty programmes directed towards the poorest and most disadvantaged groups of women, such as rural and indigenous women, female heads of households, young women and older women, refugees and migrant women and women with disabilities, recognizing that social development is primarily the responsibility of Governments;

A 2. Revise laws and administrative practices to ensure women's equal rights and access to economic resources

A 3. Provide women with access to savings and credit mechanisms and institutions



A 4. Develop gender-based methodologies and conduct research to address the feminization of poverty

#### B. Education and training of women (para 69-88)

71. Discrimination in girls' access to education persists in many areas, owing to customary attitudes, early marriages and pregnancies, inadequate and gender-biased teaching and educational materials, sexual harassment and lack of adequate and physically and otherwise accessible schooling facilities. Girls undertake heavy domestic work at a very early age. Girls and young women are expected to manage both educational and domestic responsibilities, often resulting in poor scholastic performance and early drop-out from the educational system. This has long-lasting consequences for all aspects of women's lives.

#### B 1. Ensure equal access to education

##### Actions to be taken

##### 80. By Governments:

(a) Advance the goal of equal access to education by taking measures to eliminate discrimination in education at all levels on the basis of gender, race, language, religion, national origin, age or disability, or any other form of discrimination and, as appropriate, consider establishing procedures to address grievances;

(g) Promote an educational setting that eliminates all barriers that impeded the schooling of pregnant adolescents and young mothers, including, as appropriate, affordable and physically accessible child-care facilities and parental education to encourage those who are responsible for the care of their children and siblings during their school years, to return to, or continue with and complete schooling;

#### B 2. Eradicate illiteracy among women

##### Actions to be taken

81. By Governments, national, regional and international bodies, bilateral and multilateral donors and non-governmental organizations:

(a) Reduce the female illiteracy rate to at least half its 1990 level, with emphasis on rural women, migrant, refugee and internally displaced women and women with disabilities;

#### B 3. Improve women's access to vocational training, science and technology, and continuing education

##### Actions to be taken

82. By Governments, in cooperation with employers, workers and trade unions, international and non-governmental organizations, including women's and youth organizations, and educational institutions:

(k) Ensure access to quality education and training at all appropriate levels for adult women with little or no education, for women with disabilities and for documented migrant, refugee and displaced women to improve their work opportunities.

#### B 4. Develop non-discriminatory and other educational and academic training



B 5. Allocate sufficient resources for and monitor the implementation of educational reforms

B 6. Promote lifelong education and training for girls and women  
C. Women and Health (para 89-111)

96. The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences.

101. With the increase in life expectancy and the growing number of older women, their health concerns require particular attention. The long-term health prospects of women are influenced by changes at menopause, which, in combination with life-long conditions and other factors, such as poor nutrition and lack of physical activity, may increase the risk of cardio-vascular disease and osteoporosis. Other diseases of ageing and the inter-relationships of ageing and disability among women also need particular attention.

104. Statistical data on health are often not systematically collected, disaggregated and analysed by age, sex and socio-economic status and by established demographic criteria used to serve the interests and solve the problems of subgroups, with particular emphasis on the vulnerable and marginalized and other relevant variables. Recent and reliable data on the mortality and morbidity of women and conditions and diseases particularly affecting women are not available in many countries. Relatively little is known about how social and economic factors affect the health of girls and women of all ages, about the provision of health services to girls and women and the patterns of their use of such services, and about the value of disease prevention and health promotion programmes for women. Subjects of importance to women's health have not been adequately researched and women's health research often lacks funding. Medical research, on heart disease, for example, and epidemiological studies in many countries are often based solely on men; they are not gender specific. Clinical trials involving women to establish basic information about dosage, side-effects and effectiveness of drugs, including contraceptives, are noticeably absent and do not always conform to ethical standards for research and testing. Many drug therapy protocols and other medical treatments and interventions administered to women are based on research on men without any investigation and adjustment for gender differences.

C 1. Increase women's access throughout the life cycle to appropriate, affordable and quality health care, information and related services

Actions to be taken

106. By Governments, in collaboration with non-governmental organizations and employers' and workers' organizations and with the support of international institutions:

(c) Design and implement, in cooperation with women and community-based organizations, gender-sensitive health programmes, including decentralized health services, that address





the needs of women throughout their lives and take into account their multiple roles and responsibilities, the demands on their time, the special needs of rural women and women with disabilities and the diversity of women's needs arising from age and socio-economic and cultural differences, among others; include women, especially local and indigenous women, in the identification and planning of health-care priorities and programmes; and remove all barriers to women's health services and provide a broad range of health-care services;

(o) Ensure that girls and women of all ages with any form of disability receive supportive services;

C 2. Strengthen preventive programmes that promote women's health

Actions to be taken

107. By Governments, in cooperation with non-governmental organizations, the mass media, the private sector and relevant international organizations, including United Nations bodies, as appropriate:

(a) Give priority to both formal and informal educational programmes that support and enable women to develop self-esteem, acquire knowledge, make decisions on and take responsibility for their own health, achieve mutual respect in matters concerning sexuality and fertility and educate men regarding the importance of women's health and well-being, placing special focus on programmes for both men and women that emphasize the elimination of harmful attitudes and practices, including female genital mutilation, son preference (which results in female infanticide and prenatal sex selection), early marriage, including child marriage, violence against women, sexual exploitation, sexual abuse, which at times is conducive to infection with HIV/AIDS and other sexually transmitted diseases, drug abuse, discrimination against girls and women in food allocation and other harmful attitudes and practices related to the life, health and well-being of women, and recognizing that some of these practices can be violations of human rights and ethical medical principles;

(l) Devise and implement comprehensive and coherent programmes for the prevention, diagnosis and treatment of osteoporosis, a condition that predominantly affects women;

(m) Establish and/or strengthen programmes and services, including media campaigns, that address the prevention, early detection and treatment of breast, cervical and other cancers of the reproductive system;

C 3. Undertake gender-sensitive initiatives that address sexually transmitted diseases, HIV/AIDS, and sexual and reproductive health issues.

C 4. Promote research and disseminate information on women's health

Actions to be taken

109. By Governments, the United Nations system, health professions, research institutions, non-governmental organizations, donors, pharmaceutical industries and the mass media, as appropriate:

(d) Increase financial and other support from all sources for preventive, appropriate biomedical, behavioural, epidemiological and health service research on women's health issues and for research on the social, economic and political





causes of women's health problems, and their consequences, including the impact of gender and age inequalities, especially with respect to chronic and non-communicable diseases, particularly cardiovascular diseases and conditions, cancers, reproductive tract infections and injuries, HIV/AIDS and other sexually transmitted diseases, domestic violence, occupational health, disabilities, environmentally related health problems, tropical diseases and health aspects of ageing;

#### C 5. Increase resources and monitor follow-up for women's health

##### Actions to be taken

110. By Governments at all levels, and where appropriate, in cooperation with non-governmental organizations, especially women's and youth organizations.

(d) Develop goals and time-frames, where appropriate, for improving women's health and for planning, implementing, monitoring and evaluating programmes, based on gender-impact assessments using qualitative and quantitative data disaggregated by sex, age, other established demographic criteria and socio-economic variables.

#### D. Violence against women (para 112-130)

116. Some groups of women, such as women belonging to minority groups, indigenous women, refugee women, women migrants, including women migrant workers, women in poverty living in rural or remote communities, destitute women, women in institutions or in detention, female children, women with disabilities, elderly women, displaced women, repatriated women, women living in poverty and women in situations of armed conflict, foreign occupation, wars of aggression, civil wars, terrorism, including hostage-taking, are also particularly vulnerable to violence.

D 1. Take integrated measures to prevent and eliminate violence against women

##### Actions to be taken

124. By Governments:

(i) Enact and enforce legislation against the perpetrators of practices and acts of violence against women, such as female genital mutilation, prenatal sex selection, infanticide and dowry-related violence and give vigorous support to the efforts of non-governmental and community organizations to eliminate such practices.

(m) Ensure that women with disabilities have access to information and services in the field of violence against women;

##### Actions to be taken

126. By Governments, employers, trade unions, community and youth organizations and non-governmental organizations, as appropriate:

(d) Take special measures to eliminate violence against women, particularly those in vulnerable situations, such as young women, refugee, displaced and internally displaced women, women with disabilities and women migrant workers, including enforcing any existing legislation and developing, as appropriate, new legislation for women migrant workers in both sending and receiving countries.

D 2. Study the causes and consequences of violence against women and the effectiveness of preventive measures



D 3. Eliminate trafficking in women and assist victims of violence due to prostitution and trafficking

E. Women and armed conflict (para 131-149)

131. An environment which maintains world peace and promotes and protects human rights, democracy and the peaceful settlement of disputes, in accordance with the principles of non-threat or use of force against territorial integrity or political independence and of respect for sovereignty as set forth in the United Nations Charter, is an important factor for the advancement of women. Peace is inextricably linked with equality between women and men and development. Armed and other types of conflicts and terrorism and hostage-taking still persist in many parts of the world. Aggression, foreign occupation, ethnic and other types of conflicts are an ongoing reality affecting women and men in nearly every region. Gross and systematic violations and situations that constitute serious obstacles to the full enjoyment of human rights continue to occur in different parts of the world. Such violations and obstacles include, as well as torture and cruel, inhuman and degrading treatment or punishment, summary and arbitrary executions, disappearances, arbitrary detentions, all forms of racism and racial discrimination, foreign occupation and alien domination, xenophobia, poverty, hunger and other denials of economic, social and cultural rights, religious intolerance, terrorism, discrimination against women and lack of the rule of law. International humanitarian law, prohibiting attacks on civilian populations, as such, is at times systematically ignored and human rights are often violated in connection with situations of armed conflicts, affecting the civilian population, especially women, children, the elderly and the disabled. Violations of the human rights of women in situations of armed conflicts are violations of the fundamental principles of international human rights and humanitarian law. Massive violations of human rights, especially in the form of genocide, "ethnic cleansing" as a strategy of war and its consequences, rape, including systematic rape of women in war situations, creating mass exodus of refugees and displaced persons, are abhorrent practices that are strongly condemned and must be immediately stopped, while perpetrators of such crimes must be punished. Some of these situations of armed conflict have their origin in the conquest or colonialization of a country by another State and the perpetuation of that colonization through state and military repression.

E 1. Increase the participation of women in conflict resolution at decisions-making levels and protect women living in situations of armed and other conflicts or under foreign occupation

E 2. Reduce excessive military expenditures and control the availability of armaments

E 3. Promote non-violent forms of conflict resolution and reduce the incidence of human rights abuse in conflict situations

E 4. Promote women's contribution to fostering a culture of peace

E 5. Provide protection, assistance and training to refugee women, other displaced women in need of international protection and internally displaced women

E 6. Provide assistance to the women of the colonies and non-self-governing territories



#### F. Women and the Economy (para 150-180)

F 1. Promote women's economic rights and independence, including access to employment and appropriate working conditions and control over economic resources

F 2. Facilitate women's equal access to resources, employment, markets and trade

F 3. Provide business services, training and access to markets, information and technology, particularly to low-income women

F 4. Strengthen women's economic capacity and commercial networks

#### Actions to be taken

175. By Governments:

(d) Support programmes that enhance the self-reliance of special groups of women, such as young women, women with disabilities, elderly women and women belonging to racial and ethnic minorities;

F 5. Eliminate occupational segregation and all forms of employment discrimination

#### Actions to be taken

178. By Governments, employers, employees, trade unions and women's organizations:

(f) Implement and monitor positive public and private-sector employment, equity and positive action programmes to address systemic discrimination against women in the labour force, in particular women with disabilities and women belonging to other disadvantaged groups, with respect to hiring, retention and promotion, and vocational training of women in all sectors;

(j) Ensure access to and develop special programmes to enable women with disabilities to obtain and retain employment, and ensure access to education and training at all proper levels, in accordance with the Standard Rules on the Equalization of Opportunities for People with Disabilities; 25/ adjust, to the extent possible, working conditions in order to suit the needs of women with disabilities, who should be secured legal protection against unfounded job loss on account of their disabilities;

F 6. Promote harmonization of work and family responsibilities for women and men

#### G. Women in power and decision-making (para 181-195)

G 1. Take measures to ensure women's equal access to and full participation in power structures and decision-making

G 2. Increase women's capacity to participate in decision-making and leadership

#### Actions to be taken

195. By Governments, national bodies, the private sector, political parties, trade unions, employers' organizations, subregional and regional bodies, non-governmental and international organizations and educational institutions:

(a) Provide leadership and self-esteem training to assist women and girls, particularly those with special needs, women with disabilities and women belonging to racial and





ethnic minorities to strengthen their self-esteem and to encourage them to take decision-making positions;  
 H. Institutional mechanisms for the advancement of women (para 196-209)

H 1. Create or strengthen national machineries and other governmental bodies

H 2. Integrate gender perspectives in legislation, public opinion, programmes and projects

H 3. Generate and disseminate gender-disaggregated data and information for planning and evaluation

Actions to be taken

206. By national, regional and international statistical services and relevant governmental and United Nations agencies, in cooperation with research and documentation organizations, in their respective areas of responsibility:  
 (k) Improve concepts and methods of data collection on the participation of women and men with disabilities, including their access to resources.

I. Human rights of women (para 210-233)

225. Many women face additional barriers to the enjoyment of their human rights because of such factors as their race, language, ethnicity, culture, religion, disability or socio-economic class or because they are indigenous people, migrants, including women migrant workers, displaced women or refugees. They may also be disadvantaged and marginalized by a general lack of knowledge and recognition of their human rights as well as by the obstacles they meet in gaining access to information and recourse mechanisms in cases of violation of their rights.

I 1. Promote and protect the human rights of women, through the full implementation of all human rights instruments, especially the Convention on the Elimination of All Forms of Discrimination against Women

Actions to be taken

230. By Governments:

(m) Address the acute problems of children, inter alia, by supporting efforts in the context of the United Nations system aimed at adopting efficient international measures for the prevention and eradication of female infanticide, harmful child labour, the sale of children and their organs, child prostitution, child pornography and other forms of sexual abuse and consider contribution to the drafting of an optional protocol to the Convention on the Rights of the Child.

I 2. Ensure equality and non-discrimination under the law and in practice

Actions to be taken

232. By Governments:

(p) Strengthen and encourage the implementation of the recommendations contained in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, paying special attention to ensure non-discrimination and equal enjoyment of all human rights and fundamental freedoms by women and girls with disabilities, including their access to information and services in the field of violence against women,





as well as their active participation in and economic contribution to all aspects of society;

### I 3. Achieve legal literacy

Actions to be taken

233. By Governments and non-governmental organizations, the United Nations and other international organizations, as appropriate:

(a) Translate, whenever possible, into local and indigenous languages and into alternative formats appropriate for persons with disabilities and persons at lower levels of literacy, publicize and disseminate laws and information relating to the equal status and human rights of all women, including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Rights of the Child, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Declaration on the Right to Development and the Declaration on the Elimination of Violence against Women, as well as the outcomes of relevant United Nations conferences and summits and national reports to the Committee on the Elimination of Discrimination against Women;

(b) Publicize and disseminate such information in easily understandable formats and alternative formats appropriate for persons with disabilities, and persons at low levels of literacy;

### J. Women and the media (para 234-245)

J 1. Increase the participation and access of women to expression and decision making in and through the media and new technologies of communication.

J 2. Promote a balanced and non-stereotyped portrayal of women in the media.

### K. Women and the environment (para 246-258)

K 1. Involve women actively in environmental decision-making at all levels

K 2. Integrate gender concerns and perspectives in policies and programmes for sustainable development

K 3. Strengthen or establish mechanisms at the national, regional and international levels to assess the impact of development and environmental policies on women.

### L.. The Girl child (para 259-285)

259. The Convention on the Rights of the Child recognizes that "States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political



or other opinion, national, ethnic or social origin, property, disability, birth or status" (article 2, para. 1). 10/

However, in many countries available indicators show that the girl child is discriminated against from the earliest stages of life, through her childhood and into adulthood. In some areas of the world, men outnumber women by 5 in every 100. The reasons for the discrepancy include, among other things, harmful attitudes and practices, such as female genital mutilation, son preference -which results in female infanticide and prenatal sex selection - early marriage, including child marriage, violence against women, sexual exploitation, sexual abuse, discrimination against girls in food allocation and other practices related to health and well-being. As a result, fewer girls than boys survive into adulthood.

269. Sexual violence and sexually transmitted diseases, including HIV/AIDS, have a devastating effect on children's health, and girls are more vulnerable than boys to the consequences of unprotected and premature sexual relations. Girls often face pressures to engage in sexual activity. Due to such factors as their youth, social pressures, lack of protective laws, or failure to enforce laws, girls are more vulnerable to all kinds of violence, particularly sexual violence, including rape, sexual abuse, sexual exploitation, trafficking, possibly the sale of their organs and tissues, and forced labour.

270. The girl child with disabilities faces additional barriers and needs to be ensured non-discrimination and equal enjoyment of all human rights and fundamental freedoms in accordance with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

272. All barriers must therefore be eliminated to enable girls without exception to develop their full potential and skills through equal access to education and training, nutrition, physical and mental health care and related information.

- L 1. Eliminate all forms of discrimination against the girl child
- L 2. Eliminate negative cultural attitudes and practices against girls

Actions to be taken

277. By Governments and, as appropriate, international and non-governmental organizations:

(a) Promote an educational setting that eliminates all barriers that impede the schooling of married and/or pregnant girls and young mothers, including, as appropriate, affordable and physically accessible child-care facilities and parental education to encourage those who have responsibilities for the care of their children and siblings during their school years to return to, or continue with, and complete schooling;

(c) Eliminate all forms of discrimination against the girl child and the root causes of son preference, which result in harmful and unethical practices such as prenatal sex selection and female infanticide; this is often compounded by the increasing use of technologies to determine foetal sex, resulting in abortion of female fetuses;

(d) Develop policies and programmes, giving priority to formal and informal education programmes that support girls and enable them to acquire knowledge, develop self-esteem and take responsibility for their own lives; and place special focus on programmes to educate women and men, especially parents, on the importance of girls' physical and mental health and well-being, including the elimination of discrimination against girls in food



allocation, early marriage, violence against girls, female genital mutilation, child prostitution, sexual abuse, rape and incest.

L 3. Promote and protect the rights of the girl child and increase awareness of their needs and potential

Actions to be taken

278. By Governments and international and non-governmental organizations:

(d) Facilitate the equal provision of appropriate services and devices to girls with disabilities and provide their families with related support services, as appropriate.

L 4. Eliminate discrimination against girls in education, skills development and training

Actions to be taken

280. By Governments and international and non-governmental organizations:

(c) Ensure access to appropriate education and skills-training for girl children with disabilities for their full participation in life;

L 5. Eliminate discrimination against girls in health and nutrition

L 6. Eliminate the economic exploitation of child labour and protect young girls at work

L 7. Eradicate violence against the girl child

Actions to be taken

283. By Governments and, as appropriate, international and non-governmental organizations:

(a) Take effective actions and measures to enact and enforce legislation to protect the safety and security of girls from all forms of violence at work, including training programmes and support programmes, and take measures to eliminate incidents of sexual harassment of girls in educational and other institutions;

(b) Take appropriate legislative, administrative, social and educational measures to protect the girl child, in the household and in society, from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse;

(c) Undertake gender sensitization training for those involved in healing and rehabilitation and other assistance programmes for girls who are victims of violence and promote programmes of information, support and training for such girls;

(d) Enact and enforce legislation protecting girls from all forms of violence, including female infanticide and prenatal sex selection, genital mutilation, incest, sexual abuse, sexual exploitation, child prostitution and child pornography, and develop age-appropriate safe and confidential programmes and medical, social and psychological support services to assist girls who are subjected to violence.

L 8. Promote the girl child's awareness of and participation in social, economic and political life

L 9. Strengthen the role of the family in improving the status





of the girl child

#### Chapter V. INSTITUTIONAL ARRANGEMENTS (para 286-344)

286. The Platform for Action establishes a set of actions that should lead to fundamental change. Immediate action and accountability are essential if the targets are to be met by the year 2000. Implementation is primarily the responsibility of Governments, but is also dependent on a wide range of institutions in the public, private and non-governmental sectors at the community, national, subregional/regional and international levels.

289. Non-governmental and grass-roots organizations have a specific role to play in creating a social, economic, political and intellectual climate based on equality between women and men. Women should be actively involved in the implementation and monitoring of the Platform for Action.

##### A. National level

295. The active support and participation of a broad and diverse range of other institutional actors should be encouraged, including legislative bodies, academic and research institutions, professional associations, trade unions, cooperatives, local community groups, non-governmental organizations, including women's organizations and feminist groups, the media, religious groups, youth organizations and cultural groups, as well as financial and non-profit organizations.

##### B. Subregional/regional level

303. Within their existing mandates and activities, the regional commissions should mainstream women's issues and gender perspectives and should also consider the establishment of mechanisms and processes to ensure the implementation and monitoring of both the Platform for Action and the regional platforms and plans of action. The regional commissions should, within their mandates, collaborate on gender issues with other regional intergovernmental organizations, non-governmental organizations, financial and research institutions and the private sector.

305. Non-governmental organizations within the region should be supported in their efforts to develop networks to coordinate advocacy and dissemination of information about the global Platform for Action and the respective regional platforms or plans of action.

##### C. International level

#### Chapter VI. FINANCIAL ARRANGEMENTS (para 345-361)

##### A. National level

346. The primary responsibility for implementing the strategic objectives of the Platform for Action rests with Governments. To achieve these objectives, Governments should make efforts to systematically review how women benefit from public sector expenditures; adjust budgets to ensure equality of access to public sector expenditures, both for enhancing productive capacity and for meeting social needs; and achieve the gender-related commitments made in other United Nations summits and conferences. To develop successful national implementation strategies for the Platform for Action, Governments should





allocate sufficient resources, including resources for undertaking gender-impact analysis. Governments should also encourage non-governmental organizations and private-sector and other institutions to mobilize additional resources.

350. Non-governmental organizations, the private sector and other actors of civil society should be encouraged to consider allocating the resources necessary for the implementation of the Platform for Action. Governments should create a supportive environment for the mobilization of resources by non-governmental organizations, particularly women's organizations and net-works, feminist groups, the private sector and other actors of civil society, to enable them to contribute towards this end. The capacity of non-governmental organizations in this regard should be strengthened and enhanced.

B. Regional level

C. International level

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The following were selected based on two criteria: publication or production date of 1990 or later and content of international interest.

#### Books

Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being, edited by Danuta M. Krotoski, Ph.D., Margaret A. Nosek, Ph.D., and Margaret A. Turk, M.D., published 1996 by Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624, USA, 482 pp. softcover, \$42.95. Also available on disc. This groundbreaking volume introduces the critical concept of women's health in the context of physical disabilities. It provides women with disabilities, health care professionals, and the concerned families with insights into the unique life situations experienced by women with disabilities and how these experiences affect their health. Five main sections cover: overriding issues, sexuality and reproductive health, stress and well-being, managing bladder and bowel function, and physical fitness and being.

A Woman's Guide to Coping with Disability, published 1994 by Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173, USA; Tel.: 617-862-6455, Fax: 617-861-7517, 224 pp. softcover, \$42.95. This book addresses the special needs of women with disabilities and chronic conditions, such as social relationships, sexual functioning, pregnancy, child rearing, care giving, and employment. Special attention is paid to ways in which women can advocate for their rights with the U.S. health care and rehabilitation systems. Written for women of all ages, the book has chapters on the disabilities that are most prevalent in women or likely to affect the roles and physical functions unique to women. Included are arthritis, diabetes, epilepsy, lupus, multiple sclerosis, osteoporosis and spinal cord injury.

Man-Made Medicine: Women's Health, Public Policy, and Reform, edited by Kary L. Moss, published 1997 by the Duke University Press, Dept. HLW / Box 90660, Durham, NC 27708-0660; Fax: 919-688-4574, 304 pp., \$15.95 softcover, \$49.95 library cloth edition. Man-Made Medicine makes an urgent statement about gender bias in the medical establishment and its pernicious



effects on the well-being of women and the care they receive. These essays by physicians, lawyers, activists, and scholars present a rare interdisciplinary approach to this complex set of issues. Suggesting no less than a radical rethinking of women's medicine, this book gives essential direction to the discussions that will shape the future of health care in the USA.

*The Me in the Mirror*, by Connie Panzarino, published 1994 by Seal Press, 3131 Western Avenue, Suite 410, Seattle, WA 98121, USA; Tel.: 206-283-7844, Fax: 206-285-9410, \$12.95. This is the memoir of a severely disabled activist and artist who has been living with Spinal Muscular Atrophy III since birth. Beginning in early childhood, the author tells of the complexities and challenges of growing up disabled and offers a fascinating exploration of her family relationships.

*Encounters with Strangers: Feminism and Disability* by Jenny Morris. Morris is a well-known British writer who has worked for many years to research and document the situation of women with disabilities. Published in 1996 and available for £8.99 from The Women's Press, 34 Great Sutton St., London EC1V 0DX, U.K.

*The More We Get Together: Women and Disability* edited by Houston Stewart, Beth Percival & Elizabeth R. Epperly. This 222 page text is the result of a 1990 meeting of 300 women held on Prince Edward Island as the 14th conference of the Canadian Research Institute for the Advancement of Women. The 22 papers are divided into the following topics: difference and dis/ability; herstory; caregiving and mothering; and language and writing. Published 1992 by and available for C\$12.95 from gynergy books, p.o. box 2023, Charlottetown, Prince Edward Island C1A 7N7 Canada.

*Disabled Woman* by Marja Pelkonen, Mella Villberg, Rita Jarvinen & Pirjo Markkio-Palenius. Published in 1997, this is a book born from the teamwork of four disabled women in Finland and is this the result of numerous discussions, written communications, of joy and sorrow. Through interviews and personal memories, the book provides a picture of growing up in a contemporary European society. It reflects the struggle to express individuality in an environment that is often intolerant and rejecting, in a society that only values productive individuals, and that only appreciates difference when it is freely chosen. For the reader, the text offers a journey through a world where the central question is, "Am I allowed to live, to love and to work as I am?" Topics dealt with in a straightforward manner include: unsettling childhood memories, critical assessments of schools and rehabilitation therapies, intimate accounts of sexuality and abuse, considerations of the problems and rewards of motherhood and careers. Reviewers found the book a valuable resource for all those interested in disability or any marginalized minority and an invaluable aid for discussion and therapy groups. Available for 70 Finmarks or US\$15 from National Association of the Disabled, Kumpulantie 1A, 00520-Helsinki, Finland. To contact the authors, e-mail: marja.pelkonen@invalidiliitto.fi

*Disabled Parents Dispelling the Myth* by Michele Wates is a U.K. National Childbirth Trust Guide. In this book, disabled parents share their experiences on the issues surrounding their decision to have and raise children. A 1997 review by the Royal Association for Disability & Rehabilitation (RADAR) stated that, "It is a candid account of the positive and negative aspects of the subject and details the obstacles many of these parents face and overcome: disapproval from others, dealing with physical restriction, and above all, society's inability to recognize the role of disabled people as carers when they are so tightly pigeonholed as dependents." Available from Radcliffe Medical



Press Ltd., 18 Marcham Road, Abingdon, Oxon OX14 1AA, U.K. Tel:  
44 (0) 1235 528820; e-mail medical@radpress.win-ik.net

**Gender and Disability: Women's Experiences in the Middle** East by Lina Abu-Habib, published by and available for £7.95 from Oxfam, c/o BEBC, PO Box 1496 Parkstone, Dorset BH12 3YD, U.K. or for \$9.95 from Oxfam, c/o Humanities Press, 165 First Ave., Atlantic Highlands, NJ 07716-1289 USA. Provides an overview of the neglect of disabled women by both the feminist and disability movements. A review by Disability Awareness in Action stated that the publication documents both examples of the desperate situation of disabled women in the region and examples of positive actions by and for disabled women.

**Reproductive Issues for Persons with Physical Disabilities** edited by Florence P. Haseltine, Sandra S. Cole and David B. Gray, published 1993 by Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624 USA. This 368 page text contains articles by researchers, disabled persons, medical professionals and psychologists on an array of issues including: reproductive physiology, health care needs, fertility, contraception, adoption, genetic counseling, pregnancy, labor and delivery, parenting, sexual dysfunction and sexually transmitted diseases.

**Women and Disability** prepared by Esther Boylan, published 1991 by ZED Books Ltd., 57 Caledonian Road, London N1 9BU, U.K. and ZED Books, 165 First Ave., Atlantic Highlands, NJ 07716 USA. One of a series of eight books about women and major socio-economic issues, this 110 page volume covers the situation of disabled women worldwide, focusing on issues such as violence, parenting, stigma, human rights and the needs of disabled women for greater access to education, training and employment.

**Women's Lives: Multicultural Perspectives** edited by Gwyn Kirk and Margo Okazawa-Rey, published 1997 by Mayfield Publishing Co., California USA. Among the diverse articles in this volume are several representing the viewpoints of women with disabilities, including one on reproductive rights by Marsha Saxton and one on parents with disabilities by Carol Gill.

A variety of resources for families with disabilities is available from Through the Looking Glass, 2198 Sixth St., Suite 100, Berkeley, CA 94710 USA; tel 510 848 1112; fax 510 848 4445; e-mail: TLG@lookingglass.org. In 1997, TLG held its first international conference for parents with disabilities and their families in October 1997. Examples of its publications and resources include: *Adaptive Parenting Equipment: Ideabook 1*; *Mother to Be: a Guide to Pregnancy & Birth for Women with Disabilities*; *Mother Father Deaf: Living between Sound & Silence*; *A Guide to the Adoption Option for Prospective Mothers with Disabilities & their Partners*; and *Challenges & Strategies of Disabled Parents: Findings from a National Survey*. TLG resources include a database dealing with family & disability issues; a bibliography of related books & videos; and staff who can provide technical advice & support on parenting with a disability.

**Feminism and Disability** by Barbara Hillyer, published 1997 by University of Oklahoma Press, 320 pages, available in paperback for \$13.56 from Amazon.com, the largest bookseller on the internet. This book is written from the perspective of a feminist who is also the mother of a daughter with multiple disabilities. Chapter topics include: language, productivity and pace, grief, mother blaming, nature and technology, passing, caregivers and difference, codependence and independence, and recovery programs.

**Sexuality and People with Intellectual Disability**, second edition by Lydia Pegan and Anne Rauch, published 1997 and





available for \$33 from the Paul H. Brooks publishing company, address above.

**Pushing the Limits: Disabled Dykes Produce Culture**, edited by Shelley Tremain, published 1996 and available from The Women's Press, 517 College St., Suite 302, Toronto, Ontario, Canada M6G 4A2; fax 416 921 4428. In Canada this book is available for approximately C\$16.00 but inquiries should be made regarding costs for other countries. Tremian has assembled an admirable multi-media anthology of writing, artwork, music and photography and appended a useful resource list of related cultural work.

**Across Borders: Women with Disabilities Working Together**, edited by Diane Driedger, Irene Feika & Eileen Giron Batres, published 1996 by and available for C\$14.95 from Gynergy Books, Charlottetown, Prince Edward Island, Canada. This lively 175 page collection of reports and creative writing by disabled women grew out of several years of exchange between the the International Committee of the Council of Canadians with Disabilities and peer groups in, primarily, Central America and the Caribbean, but also including Asia and Africa. The intent was to document the outcomes of women's groups in various countries working together on literacy, writing and other projects to improve their skills. Reviewers pointed out the strengths particularly of the contributions from Giron, Nugehalli Sitaram Hema and Lizzie Mamvura Longshaw.

**Women and Disability: the Experience of Physical Disability Among Women** by Susan Lonsdale. A 185 page book published 1990 by and available for L9.99 from MacMillan, Houndmills, Basingstoke, Hampshire RG21 2XS, U.K.. Fax.: 44 0256 810 526. Lonsdale interviewed 22 women with different disabilities, ages, races and socio-economic backgrounds, all of working age. The 10 resulting chapters are: Introduction; Prevalence of Disability; Social context of disability; Invisible women; Self-Image and Sexuality; Dependency; Employment; Financial consequences of disability; Discrimination and civil-rights; and Independence and self-determination.

#### Manuals, Kits & Directories

**Building Community: A Manual Exploring Issues of Women and Disability**, developed by The Women and Disability Awareness Project, this manual examines the connections between discrimination based on gender and discrimination based on disability. It contains background information on disability rights and on women and girls with disabilities, workshop formats, an annotated bibliography and selected readings. This expanded edition also contains supplementary workshop and related materials on the needs of teenagers. Available in print, braille and tape from Educational Equity Concepts, Inc., 114 East 32nd Street, Suite 701, N.Y., N.Y. 10016; fax 212 725 0947; e-mail 75507.1306@compuserve

**Bridging the Gap: A National Directory of Services for Women and Girls with Disabilities**, revised 1997 by and available from Educational Equity Concepts, Inc., address above. Contains descriptive listings of U.S. and Canada agencies and organizations providing a wide variety of services and resources for girls and women with disabilities.

**Disabled Women in Europe: A Resource Kit** was published in 1997 for the European Region of Disabled Peoples' International by Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, U.K. The 28 page kit presents data, reports and resources concerning the following issues: status of disabled women,



current legislation and policies, and current strategies for social change.

Disabled Women: Resource Kit also published in 1997 by Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, U.K.; Tel.: +44 171 834 0477, Fax: +44 171 821 9539, available in English, French, Spanish, large print, on audio-tape, ASCII computer disk and English braille, 32 pp. Developed by Disability Awareness in Action, this kit uses actual experiences of disabled women to illustrate ways in which positive changes can be effected. The illustrated text contains information on disabled women's status, attitudes, health care and rehabilitation, access to information, education and training, employment, the environment, transport and free movement, sexuality and relationships, family life and parenthood, developments in genetics, abuse and violence, female genital mutilation, and discrimination. It suggests strategies and actions for change and has comprehensive resource and contact lists.

#### Developing Countries & Community-Based Programs

Where Women Have No Doctor by A. August Burns, Ronnie Lovich, Jane Maxwell & Katharine Shapiro, published 1997 by the Hesperian Foundation, 2796 Middlefield Rd., Palo Alto CA 94306 USA. This comprehensive text of 32 chapters, available for \$17, instructs women how to identify common medical problems and outlines various treatments. The book also contains information about pregnancy, birth, violence against women and aspects of disability.

Loud, Proud & Passionate: Including Women with Disabilities in International Development Programs, a new book by Mobility International USA, 1997; Edited by Cindy Lewis and Susan Sygall. This book offers a bridge between international development organizations and women with disabilities who are working in their communities, nationally, and internationally. It informs women's and development organizations, including grassroots groups, governmental agencies, and nationally and internationally funded NGO's about why and how to actively recruit and include women with disabilities at every level of programming, as planners, directors, workers, and project members. It also informs women and girls with disabilities of the strategies and successes of disabled women in other countries, and of resources for strengthening their own development projects. Features examples of projects organized by women with disabilities; recommendations from women with disabilities who have organized from grassroots, national and international levels; practical strategies for outreach, inclusion and support of women with disabilities; resource materials and supportive organizations. Available from MIUSA, P.O. Box 3940, Eugene, Oregon 97440 USA. tel: 541-343-1284 (voice/tdd) fax: 541-343-1284; e-mail: info@miusa.org. \$12.95 Individuals: \$19.95 Organizations plus \$5 US / \$10 overseas for shipping/handling, Specify version: print, audiocassette, or diskette. Available in English now. Spanish and Russian translations available mid 1998.

Information about projects & research related to the role of women and community-based rehabilitation is available from the International Centre for Advancement of CBR, 146 Stuart St., LaSalle Bldg., Room 235, Queen's University, Kingston, Ontario, Canada K7L 3N6; tel 613 545 6881; fax 613 545 6882; e-mail: icacbr@post.queensu.ca

Information about projects in the Philippines involving disabled women in cbr is available from Carmen Reyes Zubiaga,



Technical Advisor & Acting Executive Director, Disability Resource Center, P.O. Box 877, UNV-UNDP Phnom Penh, Kingdom of Cambodia; fax 368549; e-mail: ncdp@forum.org.kh

Women Walk on Water, published 1996 by SHIA Women's Committee and available from Swedish Organization of Handicapped International Aid Foundation (SHIA), Box 4060, Magnus Ladulåsgatan 63, 102 61 Stockholm, Sweden; Tel.: +46 (0) 8 462 33 60, Fax: +46 (0) 8 714 59 22, 55 pp. During the 4th World Conference on Women, held in Beijing, China in 1995, SHIA was represented by a delegation of nine women from seven developing countries, including Nepal, Uganda, Nicaragua, Ghana, Tanzania, Thailand, and India. This report contains an account of the NGO Forum and UN Conference through the eyes of these women and includes discussions of the situation of disabled women in each of the above developing countries.

"Women on the Move", special issue of Handling, published 1995 by SHIA, address above, 31 pp. Used as a backgrounder for the SHIA delegation attending the UN 4th World Conference on Women in Beijing, this magazine includes articles on: a visit from Tanzanian women to Sweden; Awareness, a right and a duty; the visit of a Chilean girl with Down Syndrome to Sweden; disabled women in Cape Verde; visually impaired women in Vietnam; poetry from Gambia; and a discussion of women in Bangladesh and Latin America.

Disabled Women in Countries Cooperating with SHIA, a report of the compiled results of a 1993 questionnaire circulated to countries cooperating with SHIA, available from SHIA, address above, 31 pp. The replies from the questionnaire show that disabled women in the responding countries seem to have no value in their own right and people around them have no confidence in their capacity. It covers such subjects as: educational opportunities; financial independence; having a family; and decision-making power. It offers proposals for other measures, gives a summary and has an appendix of associated organizations.

#### New Publications from the International Labor Organization

Getting Hired: A Guide for Job-Seekers Who Face Barriers to Employment, by Debra A. Perry, published 1995 by the International Labor Organization, available from ILO Publications Office, CH-1211, Geneva 22, Switzerland, 47 pp. This Guide is based on the ILO project "Training-in-Industry" and its urban placement activities, which were carried out in Kenya and Tanzania with national employer federations. It was tested with its companion, "Getting Hired: A Trainer's Manual for Conducting Workshops for Job-Seekers Who Face Barriers to Employment", by the author in Kenya. It includes general rules and approaches that apply in most communities.

More and Better Jobs for Women: An Action Guide, by Lin Lean Lim, published 1996 by the International Labor Organization, address above, 193 pp., \$22.50 (25 Sw.fr., £13.50). This Guide offers advice on how to: enhance the quality of female human resources; increase investment in education and training for women; improve women's access to employment and income-earning opportunities; and ensure better terms and conditions of work and provide social protection for working women.

We Can Make It: Stories of Disabled Women in Developing Countries, by Susan Epstein, published 1997 by the International Labor Organization, address above, 50 pp, \$13.50 (15 SW.frs,





£8.10). In this book 25 disabled women from Asia, Africa and Latin America tell how they defied the odds to become educators, lawyers, farmers and shopkeepers. The women speak candidly about discrimination, motivating influences, the quest for education and employment, and the desire to be wives and mothers. They also offer advice for policy-makers to that more disabled women can achieve their potential and contribute to society.

Report on the Seminar on the Management of Enterprises for Disabled Persons under Market Economy Conditions, Prague, 16-18 May 1995, by Liba Paukert, published by the International Labor Office, address above, 64 pp. This seminar was undertaken as part of the ILO/Germany project called "Network to promote the vocational integration of vulnerable groups in Central and Eastern Europe." Its purpose was to: create awareness of the problems arising for sheltered enterprises from the transition to a market economy system; identify the main issues for which practical solutions could be found with national and international assistance; and to examine strategies for action and formulate policy recommendations. Experts from France, Germany, Sweden and the U.K. were present as well as observers from Azerbaijan, Bulgaria, Croatia, Hungary, Poland, Russian Federation and Slovakia.

## Violence

Domestic Violence and Women and Children with Disabilities, by Paul B. Feuerstein, published 1997 by the Milbank Memorial Fund, 645 Madison Avenue, New York, NY 10022, USA, 18 pp. This report cites results of studies done throughout the country and discusses policy issues from the perspectives of shelter, medical intervention, court issues, and education. It lists program initiatives including: the habilitation model; individual/group counseling; positive parenting program; and staffing models. It includes a resource list of helpful individuals as well as other groups who may offer assistance.

The connections between domestic violence & economic growth in Latin American nations is a study that was released in 1997 by the Inter-American Development Bank, 1300 New York Ave., N.W., Washington D.C. USA. Tel. 1 202 623 2846. Fax. 1 202 623 1402.

Fire in the House is a 314 page report of a regional conference on Determinants of Intra-Familial Violence and Strategies for its Elimination, held in Cambodia, organised by UNICEF & the Secretariat of State for Women's Affairs of Cambodia. Violence is interpreted as broadly as possible and includes information about many types of systemic gender discrimination as well, for example that in rural Bangladesh, studies showed malnutrition was found to be three times more common among girls than boys. Information is presented by authors from Sri Lanka, Japan, Cambodia, Malaysia, Papua New Guinea, Philippines, India, Thailand, Bangladesh, and Vietnam. Report available from UNICEF/EAPRO, GAD/CEDC Unit, P.O. Box 2-154, 19 Phra Atit Road, Bangkok 10200, Thailand; tel 662 280-5931; fax 662 280-3563.

Cutting the Rose: Female Genital Mutilation, the Practice & Prevention by Efua Dorkenoo, published 1994 and available for £15.95 from Minority Rights Group, 379 Brixton Road, London SW9 7DE, U.K.

Disabled Women & Domestic Violence Project report is available for £5 from the Waltham Forest Association of Disabled People, Alpha Business Center, South Grove, London E17 7NX, U.K.





Violence & Disabled People: a review of the literature was published in 1994 in English and French by the Roeher Institute and is available from the National Clearinghouse on Family Violence, Health Programs and Services, Health Canada, Ottawa, Ontario, Canada KIA 1B4.

Abuse of Children and Adults with Disabilities by Helen L. Westcott, a 1993 report for and available for L6.99 from the National Society for the Prevention of Cruelty to Children, 67 Saffron Hill, London EC1N 8RS, U.K.

Invisible Victims: Crime & Abuse against People with Learning Difficulties by Christopher Williams, published 1995 by Jessica Kingsley Publishers Ltd., 116 Pentonville Road, London N1 9JB, U.K.

Women with Disabilities: Survivors of Abuse, a series that appeared in 1996 and 1997 issues of Rehabilitation Digest, published quarterly by the Easter Seals/March of Dimes National Council, 90 Eglinton Ave. East, Suite 511, Toronto, Ontario M4P 2Y3 Canada.

Disability, Violence and Prevention Resources is an annotated bibliography of violence and abuse resources for people with disabilities and service providers. Over 450 pieces of information. Cost: \$20 (consumers with disabilities may be exempt). Available from the Center for Independent Living in Toronto, 205 Richmond St. W., Ste. 6055, Toronto, ON M5V 1V3. Tel.: 416 599 2458. fax.: 416 599 3555.

#### Periodicals

A Special Issue on Women & Girls of the International Rehabilitation Review was produced in 1997 and is available from Rehabilitation International, 25 East 21st Street, New York, NY, USA 10010. Tel: 1 212 420 1500; fax: 1 212 505-0871 .

One in Ten, a joint newsletter of UNICEF & Rehabilitation International reporting on childhood disability issues and projects in developing countries. Volume 17, published in 1997, was devoted to the right of disabled women to parent and the importance of disabled women acting as mentors to disabled girls. Available in English, French & Spanish from RI, address above, or UNICEF House, 3 UN Plaza, New York, N.Y. 10017 USA; fax 212 824-6483.

Portfolio, the annual report of the International Disability Exchanges and Studies (IDEAS) project. The 1996 issue includes a comprehensive report by Mobility International USA on the organization and outcomes of the International Symposium on Disabled Women, held as part of the NGO Forum associated with the 1995 UN World Conference on Women, Beijing and Hairou. Available from RI, address above.

The World Blind, magazine of the World Blind Union, published in 1997 reports on the efforts of its Women's Committee to support the development of projects for blind women around the globe. Reports focused on the results of an international conference of blind women, sponsored by the WBU in late 1996 in Canada. Magazine available in various languages and formats from World Blind Union Secretariat, La Coruna, 18, 28020 Madrid, Spain. Tel: 34 1 571 36 85; fax 34 1 571 5777.

She Can is a new biannual magazine documenting the lives and describing projects concerning women with disabilities in the Asia-Pacific Region. Details: Anuradha Mohit, Editor, National Association of the Blind, Sector 5, R.K. Puran, New Delhi 110



022, India.

New Mobility, a magazine devoted to disability culture and lifestyle, featured an international section in its 1997 issue Vol. 8, No.51. Included were reports of several women with disabilities, as well as an overview of the International Leadership Forum for Women with Disabilities by writer Laura Hershey. Details: Miramar Communications, 23815 Stuart Ranch Road, P.O. Box 8987, Malibu, CA 90265 USA. Website: <http://www.newmobility.com>; fax 310 317 9644

Disability Awareness in Action is a newsletter promoting international public awareness of disability issues. Its December 1997 issue reported on "Life, Death & Rights", an overview and news roundup concerning bioethics and disabled people. This periodical regularly covers developments concerning disabled women. Details: DAA, 11 Belgrave Road, London SW1V 1RB, U.K. Fax 44 171 821 9812; e-mail [DAA\\_ORG@compuserve.com](mailto:DAA_ORG@compuserve.com)

Disability Frontline is the newsletter of the Southern Africa Federation of the Disabled, P.O. Box 2247, 130 Herbert Chitepo Str., Bulawayo, Zimbabwe. Fax 263 9 74398. The September 1997 issue included coverage of the SAFOD women's regional committee, as do most issues.

A World Awaits You is a journal of success in international exchanges for people with disabilities, published semiannually by Mobility International USA, PO Box 10767, Eugene, Oregon 97449 USA. Fax 541 343 6812; e-mail [clearinghouse@miusa.org](mailto:clearinghouse@miusa.org). The 1997 issues included stories of several disabled women who carried out studies and exchange visits abroad.

Gender and Disability Policy, a special issue of The Journal of Disability Policy, was published in 1997 and is available for \$13 in the USA and for \$18 from other countries to cover airmail postage from the Department of Rehabilitation Education and Research, University of Arkansas, 346 N. West Avenue, Fayetteville, AR 72701 USA; fax 501 575 3253. Also available on tape or diskette. This 262 page double issue includes nine empirical and theoretical articles by scholars in disability studies, personal statements by five prominent women with disabilities who identify current issues, and book reviews of new publications on disabled women. Articles cover aspects of gender and disability differences in: education and occupation of adults with hearing loss; social security disability decisions; predictors of wages; social patterning of work disability among women in Canada; access to acute medical care; abuse of women with disabilities; mental health and women with disabilities; a feminist perspective on the social causes of impairment, disability and abuse; and an overview of arenas for policy change concerning disabled women in developing countries.

Kaleidoscope: an international magazine of literature, fine arts and disability, has produced a number of issues devoted to the creativity of disabled women. Published twice a year, back issues are available for \$5 from Kaleidoscope Press, United Disability Services, 326 Locust Street, Akron OH 44302-1876 USA. Also available on audio cassette. This artistically produced and colorfully presented magazine often contains international contributions and consistently has provocative, first rate material.

Able (active, beautiful, loving, exquisite, disabled) Women is a quarterly publication focused on today's women with disabilities who wants to achieve in all areas of her life. No subscription fee yet. Details: Abled! Newsletter, 12211 Fondren, Suite 703, Houston, TX 77035 USA; Tel. 1(713) 726-1132.



## Papers, Reports, Proceedings

Disabled Women's Sexual and Reproductive Health Resource Packet, published 1997 by the Americans With Disabilities Act and Reproductive Health Project, California Family Health Council, 1314 Lincoln Ave., San Jose, CA 95125, USA; Tel.: 408-283-9226, Fax: 408-283-9188, e-mail: bfwaxman@aol.com. This 11 page packet contains an invaluable listing of books, manuals, videos, pamphlets, equipment evaluation, listing of disabled women's rights, and bibliography of: reproductive health services; pregnancy and parenting; reproductive rights and technology; sex education; disabled women's experience; magazines and newsletters; and national technical assistance resources.

Manifesto by Disabled Women in Europe, adopted in Brussels in 1997 as a revision of recommendations from the UN Experts Seminar on Disabled Women in Vienna in 1990, and as a manifestation of the UN Standard Rules, by the European Disability Forum Working Group on Women and Disability, c/o Bruotel, Room 121/122, 4 rue de la Presse, B-Bruxelles, Belgium; Tel.: 32 2 227 11 21, Fax: 32 2 227 11 16. This 21 page Manifesto is a compilation of recommendations to improve the lives of women and girls with disabilities in the European Community. Its purpose is to inform and alert women and girls with disabilities about their position, their rights and their duties.

## Videos

An International Disability Film & Video Catalogue is being produced by Rehabilitation International and includes chapters on women's issues, disabled children and related topics. Will be available in 1998 from RI, 25 East 21st Street, New York, NY 10010, USA, Fax: 1 (212) 505-0871.

? A number of videos concerning leadership development of people with disabilities have been produced by Mobility International USA, P.O. Box 10767, Eugene, OR 97440 USA; tel 541 343 1284; fax 541 343 6812; e-mail: info@miusa.org. Among recent productions are Visions and Voices, a 15 minute overview of the participation of women with disabilities in the UN 4th World Conference on Women, held in Beijing; Emerging Leaders, documenting an international exchange and study visit among disabled and non-disabled youths from developed and developing countries; Loud, Proud, and Passionate documents MIUSA's 1997 Women's Institute on Leadership and Disability. Interviews with participants highlight the vision, determination, challenges and recommendations of women with disabilities who are grassroots leaders in over 25 countries. MIUSA's unique model of international leadership training is illustrated as women with mobility, visual and hearing disabilities are shown in training workshops and team-building activities, from project development seminars and computer training to an outdoor ropes challenge course, drumming and dancing, and camping at the Oregon coast. Captioned, English. VHS 20 minutes. Captioned Spanish and Russian versions available mid 1998. \$49. Plus shipping / handling: \$5.00 US, \$10.00 international.

Issues & Insights: a World Forum on Women with Disabilities and As We Are: from a Woman's Perspective, two videos based on the 1997 International Leadership Forum for Women with Disabilities, by Third Millennium Events, 711 Brent Road, Rockville, MD 20850 USA. The first one (15 minutes) documents the event and the second one (25 minutes) features interviews with women with disabilities from different cultures and backgrounds talking about their lives and experiences as women. Both videos are captioned in English, French and Spanish and available from





Third Millennium: tel 1 301 838 3031; fax 1 301 838 3029; e-mail: rbbieler@aol.com.

Bridges/Relationships are two strong 30 minute videos produced for the New Zealand disability television program called Bridges. The programs explore in-depth how disability has affected the relationships and marriages of couples where either the husband or wife is disabled. Ranging from mental illness to paralysis to head injury to progressive diseases, the series explores how disability has affected each couple. Some spouses were disabled prior to marriage, some following, but all speak honestly and openly about the part that disability plays in their relationships. It is also evident, after reviewing both programs, that whether the wife is the disabled or non-disabled member of the dyad, she bears the same degree of responsibility for the emotional tone and health of the relationship. Available from: Flying Start, 27 Sale Street, Freemans Bay, PO Box 47-164 Ponsonby, Auckland, New Zealand. Tel 64 09 366 7247; fax 64 09 366 7247

Ceausescu's Children is a searing 53 minute documentary on the situation of the thousands of Rumanian children abandoned to institutions when their parents could not afford to care for them. The definition of disability becomes moot in these barren, nearly unstaffed institutions since the children who were not physically or mentally disabled when they arrived, rapidly deteriorated from the lack of food, medical attention, stimulation, human interaction and hope. The women's issue here is that this situation is seen as a direct result of the Ceausescu regime's forbiddance of all forms of family planning in an economy where support of more than one child was difficult or impossible. The predictable consequence was mass abandonment of children, particularly those who were weak, disabled or female. Directed by Patricia Ingram, prize winning specialist in social issues. Available in NTSC or PAL. Available from Central Independent Television, 46 Charlotte St., London, U.K. Tel 44 171 637 4602.

Disability and Motherhood is a 25 minute exploration of the experiences of three disabled British mothers is an excellently produced presentation of the central issues confronting women with physical disabilities who decide to bear children. Issues focused on are: how they came to the decision, reaction of family and community, their adaptations to their physical limitations and their overall feelings about the experience. The mothers speak from the point of view of blindness, paralysis and cerebral palsy and interspersed with their insights and humorous observations is commentary from a British television host who is a mother and uses a wheelchair. Produced & directed by Sian Vesey, a wheelchair user, who is now a BBC producer. Available from: Fanlight Productions, 47 Halifax Street, Boston, MA 02130 USA. Tel:1 617 524 0980, Fax:1 617 524 8838. For \$149, purchase only.

I am a Beautiful Person: Sexuality & Me is a sharply edited 13 minute video presents an open, frank discussion by young adults with disabilities about: the definition of sexuality, learning about sexuality, peer pressure, parental views and the place of sexuality in relationships. There is also an accompanying workshop outline that addresses sexuality for youth with disabilities. Produced by Paula and Marge Goldberg for Pacer Center. Available in USA for sale for \$35.00; other countries must inquire about shipping costs. Available from: Pacer Center, 4826 Chicago Ave. South, Minneapolis, MN , 55417, U.S.A.. Tel 1 612 827 2966.

Key Changes: A Portrait of Lisa Thorson is a stylistic presentation on the life of a successful jazz singer who uses a





wheelchair. Interspersing performance scenes with interviews, the film successfully portrays a gutsy performance artist who demands accessibility and community visibility. The cost is \$195.

Available from Fanlight Productions, 47 Halifax Street, Boston, MA 02130, USA. Tel: 617 524 0980, Fax: 617 524 8838.

Letters from Our Lives is a documentary providing poignant portraits of the lives of disabled women in Zimbabwe through interviews of members of a women's collective. This stark panorama of how poverty, prejudice and societal ignorance intersect to keep these women on the lowest rungs of the socio-economic ladder is a valuable public education tool. "Letters from Our Lives" was the title of a special project of Disabled People's International to deliver letters from disabled women around the world to the United Nations Secretary General. Available from: Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, U.K. Tel 44 171 834 0477; fax 44 171 821 9812; e-mail 100726.141@compuserve.com

Li on Her Own Terms is an English language-subtitled Swedish 31 minute documentary focusing on how a young woman who uses a wheelchair can take charge of her own life. Produced in 1992, the film follows Li through a few days of her life, which at this moment, includes part-time work, her own apartment, an image and sound computer course, friends, reggae and sailing. There is no attempt to be didactic in this film, but clearly the underlying message is that the personal assistance services provided to her through the Swedish benefit system is crucial to enabling her to live a life of choices. A rare focus on the viewpoints and aspirations of young disabled adults, this film was produced by Curt Strombi and Malena Sioberg, commissioned by the Swedish Federation of Disabled Persons. Available from: Swedish Federation of Disabled Persons, Box 510, Vallingby, S-162 15, Sweden. Tel: 46 8 620 1856, Fax: 46 8 739 31 77

Sterilization of Leilani Muir Produced in 1996 as a 47 minute documentary for the National Film Board of Canada, this film is in actuality an indictment of the practice of eugenics in the institutions, special schools and courts of Canada. Highly recommended, this is a detailed and credentialed exploration of how a government department decides to test, evaluate and rate the ability of females in custody (jail, prison, institutions). Available from: National Film Board, Customer Services, P.O.Box 6100, Station Center Ville, Montreal, Quebec, Canada H3C 3H5. Fax: 1 514 283 7564.

The Impossible Takes a Little Longer - the resourcefulness of five disabled women who have overcome barriers in their personal and professional lives Produced in 1986 for the National Film Board of Canada, this film entertainingly presents the stories of employed women who are blind, deaf, paraplegic, quadriplegic and some combinations of these conditions. The usual points are made about the value of jobs in producing self-esteem, and the advantages of the new technologies in equalising the skill level of disabled and non-disabled employees. The charm of this film is in the small details revealed about the lives of the women interviewed. The film was directed by Anne Henderson and produced by Barbara James. Available from: National Film Board, Customer Services, P.O.Box 6100, Station Center Ville, Montreal, Quebec, Canada H3C 3H5. Fax: 1 514 283 7564

Untold Desires A 1994 Australian film that is 60 packed minutes of interviews with disabled women and men about how their disabilities have affected their approach to sexuality, relationships, motherhood and parenting. Produced by two women, it won a deserved Australian Human Rights Award, as well as a best documentary award. The film is also exceptionally well-directed, with scenes of the various disabled adults participating in sports & recreation interspersed with the "talking heads" interviews. What is most fascinating, however, is the unleavened



degree of honesty and directness demonstrated by the individuals interviews. Produced by Eva Orner of Fertile Films for Film Victoria and SBS Australia. Details from: Victorian Women with Disabilities Network, RSD 1344, Korweinguboorra, Victoria, Australia. Tel.: 3461 61 53 48 6591. Fax.:3461 61 53 48 6651. E-mail: fiona@peg.apc.org.

**Voices from the Aftermath** Produced in 1995, this 27 minute documentary was produced in Cairo by the International Committee of the Red Cross. It tells the stories of four women and children who lives have been affected by war in Israel and the occupied territories, Lebanon and Iraq. One Palestinian woman has no idea what has become of her four sons arrested in 1982 in Beirut; while another gave birth in prison with her hands and feet handcuffed. The narrator is Faten Hamama, a grande dame of Egyptian cinema who appeals as a mother to governments and armies for higher respect of humanitarian law. Available in Arabic and English. Available from the ICRC, PO Box 372, 1211 Geneva 19 Switzerland, Fax: 41 22 733 1727.

**Positive Images: Portraits of Women with Disabilities** A 50 minute documentary following the careers and lives of three disabled American women who broke through numerous barriers to find meaningful jobs and participate in the disability rights advocacy movement on city and federal levels. One woman balances the demands of a political job with raising two children, thanks to significant assistance from her husband. Glimpses of adapted cars, accessible transport and intricate support systems round out the view of life with a disability in contemporary urban America. Produced in 1989 by Harilyn Russo, an early advocate for disabled women's issues. Available from: Women Make Movies, 462 Broadway, 5th Floor, New York, NY 10013. Fax. 1 212 925 2052.

**Independent Little Cuss** A 40 minute documentary of the life of a substantially disabled woman who challenges small town, middle America with her perceptions of what her life can be. An unusually honest portrait, the video explores her family life as a young girl, her relationships with friends, parents, in-laws, lovers and siblings and proceeds through her tumultuous college days on to married life and a career. Affords an intimate look at the myriad of ways prejudice can be manifested and creative ways to combat it. The cost is \$25. 30 minutes. Available from: Jeff Patterson, 208 Leake Ave., Nashville, TN 37205. Phone. 1 615 297 3668, Fax. 1 615 352 5114.

**Whirlwind Women: Building Wheelchairs** is a 10 minute video documenting a 1997 training in Kenya for disabled African women who wanted to learn to build wheelchairs as a small business venture. The women, from throughout Uganda and Kenya, demonstrate skills, confidence and talent as they apply teamwork to produce an appropriate wheelchair from local materials which will provide mobility to people who have none. Now available in both NTSC and PAL formats for \$30 for non-profit groups from Whirlwind Wheelchairs International, San Francisco State University, School of Engineering, 1600 Holloway Ave., San Francisco, CA 94132 USA. A 60 minute version is in development and details are available from Jenny Kern, tel 510 644 1205 or e-mail: JKernes@aol.com

**No Apologies**, produced in 1994 by Peni Hall with associate producer Pandoura Carpenter, is a 28 minute documentary of a disabled women's performance group called Wry Crips. The video is an entertaining and educational compilation of performance footage and interviews with members of Wry Crips. Hall stresses that this work is written, directed, performed, produced and edited entirely by disabled and chronically ill women. Available in NTSC format for \$35 in the U.S.A. and for \$45 (includes \$10 postage) from other countries from:



Wry Crips, POBox 21474, Oakland 94620 USA; tel 510 601 5819.

The Story of Mothers and Daughters is a 70 minute made for television video featuring interviews and scenes with a wide variety of mothers and daughters. The disabled mother and daughter segment is artfully and respectfully integrated within the program, shown on network TV in 1997. Produced by Gary Weimberg, Catherine Ryan and Judith Leonard, and available from \$19.95 from Mothers and Daughters, 3411 Irving St., San Francisco CA 94122. Tel. 1 415 661 4666 or Fax.: 1 415 661 4555.

Let the Other One Live. "It was in the middle of our life, at bright noon!... November 10, 1984, you were driving to work when a tree fell on the car. It was neither a stormy nor a windy day... Human neglect? Fatality? Destiny? From now on, you are a quadriplegic and I will be your wife"... Nicole tells us the life she spent with Jacques since his accident, with the best and the worst moments. Directors: Alain Casanova and Monique Saladin. A 1996, 45 minutes video. French original version. Available from: Starfilm International: 91 rue Saint Honoré 75001, Paris, France. Tel. 33 1 40 26 11 60. Fax. 33 1 45 08 80 99.

Here, a poetry performance video by Cheryl Marie Wade, who performs her feminist works from her whirling electric wheelchair. (One of her poems, "i am not one of the..." is included in this volume.) A 13 minute production, the video is available in VHS/NTSC format as follows: \$35 for groups or organizations; \$25 for individuals; and in the PAL format for orders from other countries, prices ranging from \$45-65, depending on airmail postage. Contact: C.M. Wade, 1613 Fifth Street, Berkeley, CA 94710.

Toward Intimacy: Self-Esteem, Sexuality & Love in the Lives of Women with Disabilities, produced by Nicole Hubert and directed by Debbie McGee, is a 61 minute exploration of the lives of four women. Shot in documentary style, the film covers abuse, parenting, family relationships, marriage, sexual intimacy, reproductive rights and lesbian relationships. A Canadian National Film Board listing, it was featured in the 1993 Santa Barbara International Film Festival and the 1992 Toronto Festival of Festivals. Available as follows: in Canada only, for C\$39.95 from the National Film Board, 150 John St., Toronto, Ontario M5V 3C3, phone (in Canada only) 800 267 7710; and in the USA and other countries for \$350 purchase and \$75 rental from the Filmmakers Library, 124 E. 40th St., New York, N.Y. 10016, phone (in USA only) 800 555 9815.

Reproductive Health for Women with Spinal Cord Injury: the Gynecological Examination, produced to educate healthcare providers, but is also a good overview of what women with SCI can lobby for to improve reproductive healthcare services in their communities. A 30 minute videotape, which is sold with a studyguide, covers: management of dysreflexia during examinations, methods of transferring from wheelchair to exam table, breast examination, mammograms and pap smears. Amie B. Jackson, MD, founder of the first U.S. clinic for women with disabilities, is featured. Available in 1/2" VHS format with closed captioning for purchase for \$39.95 plus \$5 shipping (in USA only) from University of Alabama at Birmingham, Department of Physical Medicine and Rehabilitation, 1717 6th Ave. South, #506, Birmingham, AL 35233 USA. Inquire by phone 205 934 3283 regarding shipping prices for other countries.

Crazy Women: Madness, Myth & Metaphor is a 60 minute video of interviews and discussions with several American women who have been voluntarily and involuntarily committed to mental health institutions. Featured are Judy Chamberlain, Rae Unzicker, Sally Zinman, Kate Millett, Pat Weiser and Rene Bostick, many of





whom are leaders in the psychiatric survivors' movement. This is a powerful and disturbing presentation covering numerous incidences of abuse and discrimination against women who experience mental illness. Well-known author Kate Millett trades stories with the others, all of whom are articulate and impassioned about the treatment of women by the mental health system. Produced in 1990, the video is available for \$60 from Judy Levine, National Association for Rights, Protection & Advocacy, P. O. Box 16311, Rumford, RI 02916; tel 401 434 2120; and e-mail jblaaa@aol.com If using e-mail, put Crazy Women in the subject line.

Dancing from the Inside Out is a 28 minute video examining the life of primarily, female members of the Axis Dance Troupe of disabled and non-disabled performers. Although not focused on women's issues per se, quite a lot of the discussion covers body image, physical beauty, the use of movement and dance to express emotion and personality and other topics central to considerations of the development of self-esteem and confidence. Interwoven with the discussions are scenes from rehearsal and a full-scale performance by the troupe, as well as moments from their daily lives. Available for sale for \$195 plus shipping from Fanlight Productions, 47 Halifax St., Boston, MA 02130; fax 1 617 524 8838.

Vital Signs: Crip Culture Talks Back is a fascinating 48 minute documentary compilation of performances and discussions with disabled artists. Although not specifically focused on women's issues, nine of the 13 presentations/performances are by disabled women writers, comics, performance artists and activists and their work is informed by the double discrimination experienced by women who have disabilities. Featured are: Mary Duffy of Ireland and the following Americans: Cheryl Marie Wade, Carol Gill, Anne Finger, Julia Trahan, Carrie Sandahl, Elizabeth Clare, Marcy Epstein and Simi Linton. Awarded the grand prize at the 1996 Rehabilitation International Film/Video Festival, this video explores the disability arts community and finds "vital signs" that there is a disability culture alive and kicking. Produced by Sharon Snyder & David Mitchell for Brace Yourself Productions. Available for rental for \$50 a day or \$100 a week or for purchase for \$225 from Fanlight Productions, contact details above.

Shaking Off Stereotypes is a 16 minute exploration of stereotypes and prejudices about people with disabilities. It centers on a story of a woman wheelchair user who discovers her own self-worth in spite of the negative situations and judgements she encounters. Meant for small groups, the video comes with a facilitator's guide, participatory exercises, collection of personal histories, ten 24 page participant workbooks and other materials. Available for \$ 199.95 from Program Development Associates, 5620 Business Ave., Suite B, Cicero, New York 13039; tel 1 315 452 0643; fax 1 315 452 0710. Within the USA there is a 30 day free trial examination period.

#### Girls & Teenagers

See What I'm Saying is an award-winning 31 minute documentary following Patricia, a deaf child with a hearing Spanish-speaking family, through her first year of the elementary school of Gallaudet, a liberal arts university for deaf people. The focus is on how self-esteem and development is greatly enhanced by her acquisition of sign language and other communication skills. Program is open-captioned, signed, dubbed and, when needed, translated from the Spanish. Available for \$195 from Fanlight Productions, 47 Halifax St., Boston, MA 02130; fax





1 617 524 8838.

Families, Friends, Futures is a 23 minute closed-captioned video stressing the advantages of inclusion in public schools for children with severe and moderate disabilities. The film follows the development of 12 year old Betsey in the sixth grade and three year old Larissa in a community nursery school. Both girls are shown in educational and social activities. Also explored is how the progress of the girls changes their families' view of their future. Available for \$65 from Comforty Media Concepts Film Library, 22-D hollywood Ave., Hohokus, NJ 07523; fax 1 201 652 1973; e-mail [comforty@comforty.com](mailto:comforty@comforty.com)

Step by Step: Heather's Story is a 65 minute closed-captioned documentary of one child's real-life inclusion into her neighborhood school over the course of two years. The video begins when Heather, a girl with Down Syndrome, is eight years old and in "special education" and concludes two years later when she has been integrated into a fourth grade class in "regular school." This longitudinal study enables viewers to watch Heather grow along with her teachers, principal, classmates and family. Available for \$125 from Comforty Media Concepts Film Library, details above. There is also a 17 minute summary of Heather's Story available for \$65.

#### Cyberresources

Following are some women and disability-related websites and e-mail addresses concerning information resources available on the Internet. This list was prepared with the assistance of Cindy Lewis of MIUSA.

[Cal-wild@igc.org](mailto:Cal-wild@igc.org) A network of disabled women and their allies begun circa Beijing Women's Conference and maintained by women living in California.

[GnarlyBone@aol.com](mailto:GnarlyBone@aol.com) An online newsletter by artist/advocate Cheryl Marie Wade to support disability activism and culture. Not specifically for women but always contains related items of interest to them.

[Dawnn@earthlink.net](mailto:Dawnn@earthlink.net) A group dedicated to advancing networking among disability advocates

[hesperianfdn@igc.apc.org](mailto:hesperianfdn@igc.apc.org) The Hesperian Foundation is a well known publisher of low-cost health-related materials concerning women and people with disabilities. Their newest periodical is "Women's Health Exchange."

<http://www.disabilitynews.com> Newly-established disability news service. Information also available from editor, Jeanette Chranowski Leye as follows: [leye@erols.com](mailto:leye@erols.com)

<http://www.geocities.com/HotSprings/2891/abusedis.html> An information site concerning abuse of people with disabilities

<http://www.disabilitynet.co.uk/groups/dan> The website of Direct Action Network, a British group of disability activists.

<http://www.seidata.com/~marriage/rblind.html> This site contains more than 100 resources concerning blindness groups and resources.

<http://deafworldweb.org/dww> An international database, newsource and resources concerning deafness

<http://www.dpi.org/women.html> The home page of



women-related activities of Disabled People's International

<http://www.madnation.org> An advocacy group of people who have survived mental illness and its treatments

<http://www3.sympatico.ca/odell/dawnpage.html> The home page of disabled women's network (DAWN) of Ontario, Canada

<http://www.bcm.tmc.edu/crowd/> Housed by Baylor College of Medicine in Texas, this site provides information from the U.S. Center for Research on Women with Disabilities, directed by Margaret Nosek.

<http://www.wid.org/tech/handbook/> A newly published book, The Internet: an Inclusive Magnet for Teaching All Students, by Betsy Bayha, Director of Technology Policy, World Institute on Disability. Published in 1998, this book, available on the web and in print as well as in alternative formats, is aimed at helping teachers in a "hands on" approach to include all students--disabled and non-disabled--to fully explore and utilize the world wide web, cyberspace, the internet. Print and alternative format versions available for US\$5 plus postage from World Institute on Disability, 510 16th Street, Oakland, CA 94612 USA.

<http://www.arrakis.es/asoc.ies/metis>. Metis is a forum established to share information and exchange experiences concerning disabled women and violence. The forum is supported by the Daphne Initiative of the European Commission. E-mail address of the forum is: [metis-forum@bigfoot.com](mailto:metis-forum@bigfoot.com).

<http://www.windowonwellness.com> a publication from the Ohio Women with Disabilities network, focusing on health and wellness concerns.

<http://www.womenink.org> and email [wink@igc.apc.org](mailto:wink@igc.apc.org) an information and publishing source on women and development, including references on disabled women. Catalogue of over 200 titles available.

[http://women.eb.com/women/articles/Macy\\_Anne\\_Sullivan.html](http://women.eb.com/women/articles/Macy_Anne_Sullivan.html), an article on Anne Sullivan, (1866-1936), educator & companion of Helen Keller

<http://indie.ca/abilities/magazine/house.html>, a Documentary: "The Home for Blind Women"

<http://indie.ca/abilities/resourcesT.html>, multitude of information from abilities magazine, Canada

<http://www.geocities.com/hotsprings/7319/discool.htm> this site, disability cool, yields dozens of links to women's references and groups, parenting information, international issues, news, sexuality and other disability information presented with an attitude

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I Am Not One Of The

copyright 1987 by Cheryl Marie Wade

I am not one of the physically challenged-

I'm a sock in the eye with gnarled fist

I'm a French kiss with cleft tongue

I'm orthopedic shoes sewn on a last of your fears

I am not one of the differently abled-





I'm an epitaph for a million imperfect babies left untreated  
 I'm an ikon carved from bones in a mass grave at Tiergarten,  
 Germany  
 I'm withered legs hidden with a blanket

I am not one of the able disabled-

I'm a black panther with green eyes and scars like a picket fence  
 I'm pink lace panties teasing a stub of milk white thigh  
 I'm the Evil Eye

I'm the first cell divided  
 I'm mud that talks  
 I'm Eve I'm Kali  
 I'm The Mountain That Never Moves  
 I've been forever I'll be here forever  
 I'm the Gimp  
 I'm the Cripple  
 I'm the Crazy Lady

I'm The Woman With Juice

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John Kemp  
Peggy Koenig  
Danuta Krotoski  
Jim Lederman  
Cindy Lewis  
Kathy Marchael  
Carlos Martinez  
Evy Messell  
Martha Muskie  
Donna Nangle  
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Diane Svenonius



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 The ThinkQuest Team  
 Carmen Velasquez  
 Lil Di Vitorio  
 Lucy Hernandez Wong  
 The family of Ilene Zeitzer

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## Forum Program

Monday, June 16, 1997

Theme: Aspects of Leadership

Opening Ceremony

Welcoming Remarks

9.00-9.40 Kathy Martinez, Forum Director, International Division, World Institute on Disability, USA. A well known advocate for disabled women's issues, she has conducted training programs to help disability organizations develop in Central America, Europe and Africa. Her Hispanic and American Indian background has contributed to her leadership in multicultural projects.

Judith E. Heumann, Forum Co-Chair, Assistant Secretary for Special Education & Rehabilitative Services, U.S. Department of Education. A representative of the U.S. government to the Beijing Women's Conference, Heumann authored the background paper for the 1990 UN Experts Meeting on Women with Disabilities. She is her department's representative on the President's Interagency Council on Women.

Susan Daniels, Forum Co-Chair, Associate Commissioner for Disability, U.S. Social Security Administration. Dr. Daniels has been active in disabled women's issues since the 1970's when her counseling practice focused on sexuality and related issues for people with disabilities. As Commissioner one of her focuses has been to assure that disabled women receive their equal share of opportunities to participate in the labor force.

Keynote Speakers

9.40-10.15 Madeleine Albright, U.S. Secretary of State and Chair, President's Interagency Council on Women. She previously served as the U.S. Ambassador to the United Nations. In that capacity she delivered her Beijing Women's Conference speech from the "disability tent", earning the admiration of the hundreds of disabled women participants.

Donna Shalala, U.S. Secretary for Health & Human Services. As Secretary, Shalala is the country's leading spokesperson on health-related issues and personally committed her Agency as one of the main sponsors of the Forum. Her department includes several disability focused divisions including the Administration on Developmental Disabilities.

Recognition

10.15-10.25 Kathy Martinez: Recognition of International Organizers & Forum Sponsors

Keynote Address

10.25-10.55 Maria Rantho, Member of Parliament, South Africa. Rantho is one of the leaders who rose from the grassroots apartheid struggles in South Africa to fight for the recognition

Monday, June 15, 1959

Topic: ...

Opening Ceremony

Following Remarks:

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 11:45-12:00 ...

of human rights of disabled people in the new Constitution, one of the world's first to outlaw discrimination based on disability.

#### Session Close

10.55-11.00 Kathy Martinez

11.00-11.30 Tea Break

#### Keynote Address

11.30-12.30 Laura Liswood, USA, founder, Women's Leadership Project, presents and discusses her videotaped interviews with female Heads of State. She has interviewed 15 current and former women Presidents and Prime Ministers including the Presidents of Nicaragua, Iceland, Ireland and the Philippines; and Prime Ministers of Norway, Turkey, Pakistan, Sri Lanka, the U.K. and Dominica for this book and video project.

12.30-14.00 Lunch and Speakouts for European Region and Middle East

#### 14.30-17.30 - Workshops

##### WORKSHOP A

##### Organizational Development

The steps to building an organization and making it effective

Co-Chairs: José Gregori (Brazil)

Hema Sitaran (India)

##### Presenters:

Lina Chowdury (Bangladesh)

Elisa Pelkonen (Finland)

Dorothy Musakanya (Zimbabwe)

Gertrude Fefoame (Ghana)

##### WORKSHOP B

##### UN Conventions: Practical Applications

Examples of how to apply international agreements on a local level

Co-Chairs: Susan Parker (USA)

Kicki Nordstrom (Sweden)

##### Presenters:

Ratna Ibrahim (Indonesia)

Akiko Ito (UN)

Anneli Joneken (Sweden)

Lucy Hernandez Wong (USA)

Angela King (UN)

##### WORKSHOP C

##### Proposal Writing

Ways to make your ideas more attractive to funders

Co-Chairs: Venus Ilagan (Philippines)

Joan Leon (USA)

##### Presenters:

Suzanne Reier (USA)

Cindy Lewis (USA)

Eileen Girón (El Salvador)

Yutta Fricke (Canada)

Kadimala Fatuma Achan (Uganda)

##### WORKSHOP D

##### Independent Living

Models of services developed by disabled people for disabled people

Co-Chairs: Marca Bristo (USA)

Carmen Reyes (Cambodia)





Presenters:

Naomy Ruth Esiaba (Kenya)  
 Anne-Marie Hughey (USA)  
 Masako Okuhira (Japan)  
 Katia Moura (Brazil)  
 Gordana Rajkov (Yugoslavia)

WORKSHOP E

Organizing for Systems Change  
 Strategies for effecting policy, legislation and service delivery

Co-Chairs: Susan Sygall (USA)  
 Phindi Mavuso (S. Africa)

Presenters:

Pat Wright (USA)  
 Susan Chitimbe (Malawi)  
 Jane Campbell (UK)  
 Petrona Sandoval (Nicaragua)  
 Charlotte McClain (S. Africa)  
 Alejandra Poveda (Costa Rica)

WORKSHOP F

Community Organizing  
 Designing and implementing grassroots strategies

Co-Chairs:

Farida Gulamo (Mozambique)  
 Celia Leão (Brazil)

Presenters:

Justine Kiwanuka (Canada)  
 Foluke Idowu (Nigeria)  
 Devva Kasnitz (USA)

17.45-19.30 - Special Sessions

Research Focus Group I

Special Forum focus group

Chair: Suzanne Reier (USA)

Reier and Tanis Doe are coordinating all Forum research initiatives

Implementation of the Americans with Disabilities Act

Chair: Diedre Davis (USA)

Liz Savage (USA)

Arlene Mayerson (USA)

Juliana Recio (USA)

Integration Through Recreation

Examples and models

Chair: Susan Sygall (USA)

Susie Grimes (USA)

Irma Rolander (Mexico)

Disabled Peoples' International Women's Caucus

18.00-22.00 - Evening: Visit to disability technology  
 superstore/selected disability videos

Tuesday, June 17, 1997

Theme: Education & Development Assistance

9.00-10.30

Co-Chairs: Judith Winston, Under Secretary of Education  
 (Acting), General Counsel, U.S. Department of Education. Winston  
 has worked as a lawyer on a variety of civil rights, race, and  
 gender equity issues, and was deputy director for public policy  
 at the Women's Legal Defense Fund in Washington.



Josephine Sinyo, Forum for African Women Educationalists (FAWE), Kenya. An attorney, Sinyo is a member of the Task Force to review the laws on women, children and persons with disabilities, with emphasis on domesticating the international Conventions.

Keynotes: Richard Riley, Secretary, U.S. Department of Education. Secretary Riley has devoted substantial time during the last two years to working with Congress on the re-authorization of the Individuals with Disabilities Education Act (IDEA), which passed in May 1997. This is the keystone legislation which provides free and appropriate educational services to all children and youth with disabilities.

Judith E. Heumann, Assistant Secretary, U.S. Department of Education

Brigitta Andersson, SHIA, Sweden. Andersson administers SHIA, an organization which for 15 years has been focused on providing financial and other support to organizations of disabled people in Africa and Asia. SHIA is a model for how foreign aid or development assistance can assist disabled people.

Marca Bristo, Chair, National Council on Disability, USA. NCD is the U.S. government agency charged with the leading role in developing disability policy and keeping the President and Congress apprised of progress and problems in this sphere. Bristo is a leader in the development of independent living programs and a specialist in disabled women's issues.

Yukiko Nakanishi, Japan. Nakanishi is the founder and President of the Asia Disability Institute, Japan and a member of the Advisory Panel on the Implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons. Formerly, she served as a Programme Specialist for the UN Economic and Social Commission for Asia and the Pacific (ESCAP).

10.30-11.00 Tea Break

11.00-11.15 Audio visual highlights: "Visions and Voices from Beijing"

11.15-12.30 Plenary: National Follow-up to the Beijing Platform for Action

Co-Chairs: Lucy Hernandez Wong, Executive Director, Disabled Peoples' International. One of the core leaders of the disability caucus of the Beijing Women's Conference, she has substantial international experience in disabled women's issues.

Kicki Nordström (Sweden), Vice President, World Blind Union. Nordström has been the central organizer of WBU's extensive activities for blind women and represented WBU at the Beijing Women's Conference.

Presenters: Anneli Joneken (Sweden), Fatima Mansuri (Pakistan), Alejandra Poveda (Costa Rica), Juliet Mupurua (Namibia), Marja Pihlala (Finland), Li Dongmei (China), Liu Jiarong (China)

12.30-14.00 Lunch and Speakouts for Asia/Pacific Region

14.30-17.30 - Workshops

#### WORKSHOP A

Mentoring & Peer Education

Providing disabled girls and women with role models and support



Co-Chairs:Salma Maqbool (Pakistan)  
Yolan Koster-Dreese (Netherlands)  
Presenters:  
Harilyn Roussso (USA)  
Lizzie Mamvura (Zimbabwe)  
Marcia Segura (Peru)  
Zohra Rajah (Mauritius)  
Monica Bartley (Jamaica)  
Agnes Noonan (USA)

#### WORKSHOP B

Development Assistance Models  
Bilateral and regional financial support for disability projects  
in developing countries  
Co-Chairs:Yukiko Nakanishi (Japan)  
Maria Rantho (South Africa)  
Presenters:  
Susan Sygall (USA)  
Barbro Carlson (Sweden)  
Sebe Matsebula (Swaziland)  
Tamara Zolotseva (Russia)  
Francine Arsenault (Canada)

#### WORKSHOP C

Research & Disability Studies  
This Workshop will discuss aspects of the participatory action  
research to be conducted during the Forum  
Co-chairs:  
Katherine D. Seelman (USA)  
Jeanette Harvey (USA)  
Presenters:  
Tanis Doe (Canada)  
Adrienne Asch (USA)  
Lynita Conradie (Namibia)

#### WORKSHOP D

Strategies for Educating Disabled Girls & Women  
Discussion to develop a common agenda on how to maximize the  
number of disabled girls entering and completing school  
Co-Chairs:  
Judith E. Heumann (USA)  
Tanya Almeida (Brazil)  
Presenters:  
Beatriz Mitchell (USA)  
Angelica Agudo (El Salvador)  
Eudalie Wickham (Barbados)  
Nguyen Hong Ha (Vietnam)  
Catherine Boldt (Canada)  
Josephine Sinyo (Kenya)  
Rhonda Weiss (USA)

#### WORKSHOP E

Access to Higher Education  
Increasing opportunities in college & other post secondary  
programs  
Co-Chair:  
Maureen McLaughlin (USA)  
Presenters:  
Devva Kasnitz (USA)  
Norman Coombs (USA)  
Rhona Hartman (USA)

#### WORKSHOP F

Literacy Projects  
Initiatives including and by women with disabilities  
Co-Chairs:Carol Rasco (USA)\*  
Patricia McNeil (USA)\*  
Presenters:



Claudia Santiago Gonzalez (Mexico)  
 \* Presenting also

# 17.45-19.30 - Special Sessions

African Caucus Meeting  
 Chair: Lizzie Mamvura (Zimbabwe)

Research Focus Group II  
 Special Forum focus group  
 Chair: Tanis Doe (Canada)

Disabled Women in Sports  
 Chair: Alicia Contreras (Mexico)  
 Susie Grimes (USA)  
 Martha Heredia Navarro (Mexico)  
 Rosana Bastos (Brazil)

Adoption Issues  
 Chair: Debby McFadden (USA)\*  
 Syd Jacobs (USA)  
 Trish Day (USA)

Writing Projects  
 Chair: Connie Panzarino (USA)\*  
 Diane Driedger (Canada)  
 Maria Luiza Camara (Brazil)

20:00-23:00 - Evening: Talent Night

Wednesday, June 18, 1997

Theme: Health & Family Issues

9.00-10.30  
 Co-Chairs: Vivian Pinn, Director, Office of Research on Women's Health, National Institutes of Health, the first fulltime appointment for this position. She has long been active in efforts to improve the health and career opportunities for women and minorities and has been given several honors for her contributions in the field of medicine.

Susan Parker, Secretary General, Rehabilitation International. Previously, Parker served as Associate Commissioner for Disability, Social Security Administration, and as Commissioner, Maine Department of Mental Health and Mental Retardation. Since becoming Secretary General in 1994 she had advocated for the organization's stronger involvement in the worldwide anti-landmine campaign and worked with UN Specialized Agencies to elevate disability policy in their work.

Keynotes: Mary O'Hagan, New Zealand. O'Hagan was founding president of the World Association of Psychiatric (Service) Users, comprised of national groups of people who have used mental health systems and are working to improve them. She has had substantial experience with the New Zealand mental health system and studied systems in Europe and North America.

Lesbia Solarzano, CEPRI, Nicaragua. Founder of CEPRI, a disabled persons' organization, she is a longtime advocate for people with disabilities and has worked as a grassroots organizer in Nicaragua. Solarzano is a medical doctor.

Dr. Lyubov Trafimovna Popova, Russia. Dr. Popova, a physician with a disability, was the senior representative from Siberia to the Beijing Women's Conference. Recently her focus has been the





development of Russia's first health clinic for disabled women, based in Novosibirsk.

Marsha Saxton, USA, is a member of the working group on the Ethical, Legal and Social Implications Program of the U.S. Human Genome Initiative, National Institutes of Health and Department of Energy. Saxton is the 1997 Ed Roberts Post-Doctoral Fellow, University of California, Berkeley School of Public Health.

10.30-11.00      Tea Break

11.00-11.30      Audio-visual highlights: Disability and Motherhood

11.30-12.30      Workshop leaders will introduce the theme of health and family issues

12.30-14.00      Lunch and Speakouts for Latin American Region

14.30-17.30 - Workshops

#### WORKSHOP A

Reproductive Issues

Discussion of ethical and genetic issues related to bearing children

Co-Chairs:

Danuta Krotoski (USA)

Alcida Perez (PAHO)

Presenters:

Sandra Welner (USA)

Antonina Basktykina (Russia)

Junko Sakaiya (Japan)

Peninah Mutinda (Kenya)

Marsha Saxton (USA)

#### WORKSHOP B

Parenting & Family Issues

Problems and solutions from the perspective of women with disabilities

Co-Chairs:

Merle McPherson (USA)

Euphrasia Mbewe (Zimbabwe)

Presenters:

Judi Rogers (USA)

Diane Afes (USA)

Kim Mi Yeon (Korea)

Alexia Muningura (Namibia)

Kadimala Fatuma Achan (Uganda)

Pat Laird (USA)

#### WORKSHOP C

Violence Against Girls & Women with Disabilities

Reports & projects on this issue

Co-Chairs:

Pat Broderick (USA)

Veronica Robinson (USA)

Presenters:

Nora Groce (USA)

Phan Thi Bich Diep (Vietnam)

Shirley Masuda (Canada)

Tanis Doe (Canada)

Bonnie Campbell (USA)

Robin Toucy Aires (USA)

#### WORKSHOP D

Sexuality



Education about and recognition of sexual issues of disabled women

Co-Chairs:

Corbett O'Toole (USA)

Marca Sipski (USA)

Presenters:

Elizabeth Caetano (Brazil)

Amy Jackson (USA)

Dinah Radtke (Germany)

Barbara Faye Waxman (USA)

America Larrainzar (Mexico)

Irene Feika (Canada)

Mary Duffy (Ireland)

#### WORKSHOP E

Health & Wellness: Prevention of Secondary Disabilities

Various aspects of prevention of secondary conditions among people who are already disabled

Co-Chairs:

JoAnn Thierry (USA)

Gulbadan Habibi (UNICEF)

Presenters:

Sushila Paudel (Nepal)

Margaret Turk (USA)

Sunny Roller (USA)

Monica Bartley (Jamaica)

Catherine Bontke (USA)

#### WORKSHOP F

Developing Health Services and Clinics for Disabled Women

Co-Chairs:

Martha Muskie (USA)

Susan Blumenthal (USA)

Presenters:

Judy Panko Reis (USA)

Lyubov Trafimovna Popova (Russia)

Laura Rauscher (USA)

Belsem Zmantar-Boussetta (Tunisia)

17.45-19.30 - Special Sessions

Research Focus Group III

Special Forum focus group

Chair: Fiona Strahan (Australia)

"Ask the Doctor"

Chair: Danuta Krotoski (USA)

Sandra Welner (USA)

Margaret Turk (USA)

Pamela Ballard (USA)

"Ask the Doctor"

Chair: Ilene Zeitzer (USA)

T. San Agustin (Philippines)

Amy Jackson (USA)

Catherine Bontke (USA)

Lesbia Solarzano (Nicaragua)

"Ask the Doctor"

Chair: JoAnn Thierry (USA)

Julie Madorsky (USA)

L. Trafimovna Popova (Russia)

Marca Sipski (USA)

\*\*Ask the Doctor"

Informal sessions covering aspects of reproductive issues, sexuality, access to health services and prevention of secondary conditions. Each session will have specialists in these areas to answer questions from the audience.



21.00-23.00 - Films Related to Theme

Thursday, June 19, 1997

Theme: Employment Strategies

9.00-10.30 Co-Chairs:

Ilene Zeitzer, U.S. Social Security Administration. Serving as Special Assistant in the Office of Disability, Zeitzer has focused on international programs and research to determine effective ways for disabled people to enter or re-enter the work force. In this capacity, she has been the project director for several international comparative studies of the situation of disabled people in the labor market.

Aida Alvarez, Administrator, U.S. Small Business Administration and member of the President's Cabinet. Formerly she has held positions as a government financial regulator, investment banker and journalist and is the first Hispanic person to hold a position in the President's Cabinet.

Keynotes: Susan Daniels, U.S. Social Security Administration

Pauline Winter, Chief Executive Officer, Workbridge, New Zealand. Workbridge is a novel national approach to assisting disabled people to train for jobs or to obtain employment. Of Maori background, Winter has first-hand experience with discrimination against disadvantaged or marginalized groups.

Ruby Gonzalez Myers, Philippines. Gonzalez has built up a substantial import/export business in the Philippines utilizing the skills of workers with disabilities. Her efforts have been featured in the award-winning international film, "Business as Usual".

Evy Messell, ILO. Messell is a long established ILO expert on women in the labor force and has recently joined the ILO Headquarters team which initiates and supports projects in employment of disabled persons.

10.30-11.00 Tea Break

11.00-11.30 Audio-visual highlights: employment issues

11.30-12.30 Workshop leaders will introduce the theme of employment strategies

12.30-14.00 Lunch and speakouts for African Region

14.30-17.30 - Workshops

WORKSHOP A

Income Generating Models

Description of projects which have been successful in providing employment on a small business basis

Co-Chairs:

Rona Moyo (Zimbabwe)

Funmi Bickersteth (Nigeria)

Presenters:

Linda Wilson (USA)

Bileen Girón (El Salvador)

Peninah Mutinda (Kenya)

Karen Ngai (Hong Kong)



Sookwarie Ram (Trinidad/Tobago)  
 Dorothy Musakanya (Zimbabwe)  
 Lizzie Mamvura (Zimbabwe)

#### WORKSHOP B

Employment on the Macro Level  
 Describes legislation, policies or national initiatives which are improving job possibilities

##### Co-Chairs:

Carolyn Colvin (USA)  
 Tuula Haatainen (Finland)

##### Presenters:

Pauline Winter (New Zealand)  
 Sushila Paudel (Nepal)  
 Tamara Zolotseva (Russia)  
 Teresinha Mauro Miranda (Brazil)

#### WORKSHOP C

Training & Job Counseling  
 Innovative approaches to preparing for employment

##### Co-Chairs:

Diane Svenonius (USA)  
 Ellen Thrasher (USA)

##### Presenters:

Dorothy Musakanya (Zimbabwe)  
 Lilia Pinto (Brazil)  
 Roseanne Ashby (USA)  
 Phan Thi Bich Diep (Vietnam)  
 Jennie D. Rundell (USA)  
 Ellen Golden (USA)

#### WORKSHOP D

Business Planning & Fundraising  
 Steps to implementing business plans & fundraising campaigns

##### Co-Chairs:

Margaret Staton (USA)  
 Kathy Martinez (USA)

##### Presenters:

Maria Eugenia Antuñez (Mexico)  
 Safia Nalulue (Uganda)  
 Karla Rivas (Guatemala)  
 Ndèye Ndagué Gueye (Senegal)  
 Ruby Gonzalez (Philippines)

#### WORKSHOP E

Access to the Job Market  
 Practical strategies toward gaining employment with government agencies and other large employers

##### Co-Chairs:

Angela Traiforos (USA)  
 Heather Williams (Ireland)

##### Presenters:

Carmen Fogaça (Brazil)  
 Simi Litvak (USA)  
 Debra Perry (USA)  
 Julie Huber (USA)  
 Judy Gilliam (USA)  
 Mary Strand (USA)

#### WORKSHOP F

Inclusion Through Transportation  
 Approaches to providing accessible transportation

##### Chair:

Trish Day (USA)

##### Presenters:

Maria Paula Teperino (Brazil)  
 Louise Stoll (USA)  
 Christine Lee (Malaysia)





17.45-19.30 - Special Sessions

Asia/Pacific Caucus

Chair: Ratna Idraswari (Indonesia)

Whirlwind Women

Demonstration of wheelchair building by women wheelchair riders

Chair:

Jennifer Kern (USA)

Latin American Caucus

Chair: Petrona Sandoval (Nicaragua)

Agricultural Methods

Chair: Jill Long Thompson (USA)

Panel Discussions: Ophelia Falls, Anne F. Thomson Reed, Denise Decker (USA)

Research Focus Group IV

North American & European Caucus

Elisa Pelkonen (Finland)

20.00-23.00 - Evening: Farewell Party

Friday, June 20, 1997

Theme: Communication & Technology

9.00-10.30

Co-Chairs: Barbara Duncan, Director of Communications and Editor, International Rehabilitation Review, Rehabilitation International

Dinah Cohen, U.S. Department of Defense. Cohen is the Director of the Computer Adaptation for People with Disabilities Program, the Department of Defense's wide ranging initiative to supply adaptive, appropriate technology to all its employees who need it. She is also active in the United States Council for International Rehabilitation, working to improve worldwide application of adaptive technology.

Keynotes: Katherine D. Seelman, Director, National Institute on Disability and Rehabilitation Research, U.S. Department of Education. She has served as an administrator, researcher and advocate in disability policy, with research experience including positions at the National Council on Disability and the Gallaudet Research Institute.

Rina Gill, UNICEF Bangladesh. Gill has worked for many years to help UNICEF improve audio-visual and print communications about women, children with disabilities, and, most recently, the girlchild. She has challenged long-established assumptions that fear is the best motivator to convince people to utilize health and prevention services.

Salma Maqbool, World Blind Union, Pakistan. Working many years for both the World Blind Union and the local Disabled Peoples' International organization, Maqbool is a specialist in media issues concerning disability. She has organized numerous workshops and training seminars to educate disabled people on how to represent themselves in the mass media.

Rachel Hurst, Disability Awareness in Action, UK. A founder of



England's first independent living center, Hurst has been at the forefront of the international disability rights movement since the 1970s. One of her specializations has been the improvement of the image and status of disabled people through their own production of public education campaigns in all media.

Deborah Kaplan, Issue Dynamics, Inc., USA. Kaplan has been the leading disabled female advocate for the recent U.S. legislative efforts to build needs of the disabled population into federal standards and requirements for new communication and information technology. She is credited as a main force behind the momentum to create "electronic curbcuts on the information highway".

10.30-11.00      Tea Break

11.00-11.30      Audio-visual highlights: High and Low Technology Videos

11.30-12.30      Workshop leaders will introduce theme of Communication & Technology

12.30-14.00      Lunch and speakouts for North American/Caribbean Regions

14.30-17.30 - Workshops

#### WORKSHOP A

Universal Design

Examples of the application of architectural and technological design for all

Co-Chairs:

Deborah Kaplan (USA)

Judy Fein (USA)

Presenters:

Betsy Bayha (USA)

Judy Brewer (USA)

Alexandra Enders (USA)

Silvana Cambiaghi (Brazil)

Jan Sing (USA)

#### WORKSHOP B

Accessing the Internet

Exploring disability sites and accessible pathways to the information highway

Co-Chairs:

Dinah Cohen (USA)

Paul Ackerman (USA)

Presenters:

Carl Raskin (ILO)

Steve Jacobs (USA)

Susan Brummel (USA)

Norm Coombs (USA)

#### WORKSHOP C

Small Budget Media Projects

Developing low cost, effective disability materials

Co-Chairs:

Kathy Marchael (USA)

Sebe Matsebula (Swaziland)

Presenters:

Rina Gill (Bangladesh)

Suzanne Levine & Patricia Chadwick (USA)

Sawart Pramoonslip (Thailand)

Florence Nayiga (Uganda)

Rachel Hurst (UK)



WORKSHOP D

Appropriate Technologies & CBR

Providing technology and CBR in developing countries and rural areas

Co-Chairs:

Ralf Hotchkiss (USA)

Fatuma Achan (Uganda)

Presenters:

Drekine H. Gacou (Mali)

Jennifer Kern (USA)

Carmen Reyes Zubiaga (Cambodia)

Ratna Ibrahim (Indonesia)

Francine Arsenault (Canada)

WORKSHOP E

Disability Culture & the Arts

Renowned women artists with disabilities will discuss important elements of arts and culture that impact women internationally.

Co-Chairs:

Anne Finger (USA)

Ann Cody (USA)

Presenters:

Sian Vasey (UK)

Beth Caetano (Brazil)

Nancy Becker Kennedy (USA)

Riua Akinshegun (USA)

Sharifa Mirembe (Uganda)

Isabella Ferrara (USA)

WORKSHOP F

Working with the Media

Improving disability images through mass communication

Co-Chairs:

Barbara Duncan (USA)

Salma Maqbool (Pakistan)

Presenters:

Jean Parker (USA)

Tuuliki Nekundi (Namibia)

Fatima Mansuri (Pakistan)

Barbara Kolucki (USA)

Sian Vasey (UK)

17.45-17.45 - Tea Break

17.45-19.00 - Closing Ceremony

Judith E. Heumann, Forum Co-Chair

Susan Daniels, Forum Co-Chair

Kathy Martinez, Forum Director: Closing Remarks

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Honorary Chair

U.S. First Lady Hillary Rodham Clinton

Co-Chairs

Judith E. Heumann, Assistant Secretary, Special Education and  
Rehabilitative Services,  
Department of Education

Susan Daniels, Associate Commissioner for Disability, Social  
Security Administration





## Forum Organizers

World Institute on Disability  
Rehabilitation International  
Mobility International USA

## Forum Executive Committee

Judith E. Heumann, Forum Co-Chair  
Susan Daniels, Forum Co-Chair  
Kathy Martinez, Forum Director  
Rosangela Berman-Bieler, Event Coordinator  
Ilene Zeitzer, U.S. Social Security Administration  
Margaret McLeod, Department of Education  
Katherine D. Seelman, National Institute on Disability and  
Rehabilitation Research  
(NIDRR)  
Paul Ackerman, (NIDRR)  
Barbara Duncan, Rehabilitation International  
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  - National Institutes of Health  
  . National Center for Medical Rehabilitation Research, National  
  Institute of Child Health and Human Development  
  . Office of Research on Women's Health  
- Health Resources and Services Administration  
  . Maternal and Child Health Bureau, Division of Services for  
Children with  
  Special Health Care Needs

U.S. Social Security Administration  
- Office of Disability  
- Office of Systems

U.S. Department of Defense  
- Computer/Electronic Accommodations Program

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- Deputy Assistant Secretary for EEO and Civil Rights



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- Office of the Secretary
- Office of Intermodalism
- Federal Highway Administration
- Federal Transit Administration

U.S. Small Business Administration

- Office of Women's Business Ownership

U.S. Department of Education

- Office of Special Education and Rehabilitative Services
- . National Institute on Disability and Rehabilitation

Research

- . Office of Special Education Programs
- . Rehabilitation Services Administration
- . Office of Elementary and Secondary Education
- . Office of Post-Secondary Education

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- ? U.S. + Cuba Medical Project
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- ? Very Special Arts
- ? World Bank
- ? World Learning

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# Participating Countries & Territories

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The following list of materials include all the products of the International Leadership Forum for Women with Disabilities and information about where to obtain them. To request any of the products listed, please fill out the form on next page and fax or mail it to the related organization, as indicated below.

? Resource Kit on Women with Disabilities: a set of three disks with documents, abstracts and other information related to women with disabilities issues and the address list of Forum participants. Cost including shipping and handling: \$15 in the US and \$20 worldwide. Available from Third Millennium Events, 711 Brent Road, Rockville, MD 20850, USA. Tel. 1(301)838-3031, Fax. 1(301)838-3029, Email. RBbieler@aol.com.

? Issues & Insights: a World Forum on Women with Disabilities and As We Are: From a Woman's Perspective, two videos (15 min and 20 min.) produced by Third Millennium Events, based on the 1997 International Leadership Forum for Women with Disabilities. The first video documents the event and the second video features interviews with women coming from different regions of the world and cultural backgrounds. Both videos can be used as a training resource on women with disabilities issues and are available with English, French or Spanish subtitles. Cost of a tape with the two videos, including shipping and handling: \$45 in the US and \$50 worldwide. Special 25% discount for non-profit organizations from developing countries. Available from Third Millennium Events, address above.

? Additional copies of Forum Final Report: Cost including Shipping and handling: \$40 in the US and \$45 worldwide. Also available in Braille and on disc from Rehabilitation International, 25 East 21st Street, New York, NY 10010 USA. Tel. 1(212)420-1500, Fax. 1(212) 505-0871, TDD. 1(212) 420-1752, Email. Rehabintl@aol.com. Discounts available for groups in developing countries.

? The International Rehabilitation Review (RI, Volume 48, Issue 1, January-June, 1997), Special Issue on Women and Girls: Cost including shipping and handling: \$20 in the US and \$25 worldwide. Also available on disc from Rehabilitation International, address above.

? One in Ten (RI/UNICEF, Volume 17, 1997) - Girls and Women with Disabilities: Issues & Initiatives: Available in English, French or Spanish from UNICEF, Child Protection Section, 3 UN Plaza, New York, NY 10017 USA; fax. 1 212 824 6483.

? Two Reports by Tanis Doe, Ph.D. on: Evaluation of the Forum and Research conducted with Forum Focus Groups, in disc format only. Shipping and handling: \$15 in the US and \$20 worldwide. Available from the World Institute on Disability, 510 16th Street, Suite 100, Oakland, CA 94612 USA; fax: 1(510)763-4109.

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Forum Products Form

International Leadership Forum for Women with Disabilities

(To request any of the products listed, please fill out this form and



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How many sets? Total Cost:

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( ) Two Reports by Tanis Doe, Ph.D. on: Evaluation of the Forum and Research conducted with Forum Focus Groups, in disc format only.

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## Forum Organizers

The Forum was organized as a collaboration among the groups listed below.

The World Institute on Disability (WID) is a non-profit organization whose purpose is to improve the quality of life of persons with disabilities throughout the world. Founded in 1983 by leaders of the Independent Living Movement as a center for the study of public policy on disability and independent living, WID main focuses include research, public education, technical assistance and training concerning issues that impact the ability of people with disabilities to live independently.



The Board was organized as a collaboration among the various  
 United States  
 The Board consists of representatives from the various  
 departments and agencies of the Government, and is  
 organized to coordinate the activities of the  
 various departments and agencies in the  
 field of public health and safety.  
 The Board is organized into several committees  
 and subcommittees, each of which is  
 responsible for a specific area of  
 activity. The Board meets regularly to  
 discuss the activities of the various  
 departments and agencies, and to  
 coordinate their efforts in the  
 field of public health and safety.

WID's staff includes researchers, teachers, trainers, policy analysts, disability activists and public health specialists. Based in Oakland, California, both WID's staff and board are comprised of a majority of people with disabilities.

Founded in 1922, Rehabilitation International (RI) is a worldwide network of people with disabilities, service providers and government agencies working to improve the quality of life for disabled people. Placing major emphasis on the exchange of practical experience in developing policies and programs, RI maintains four year cycles of meetings and regional events building to a World Congress.

RI, based in New York, places great value on its consultative status with the United Nations and its family of specialized agencies, including: UNICEF, ILO, WHO, UNESCO as well as the European Union, the Organization of American States, the UN Economic and Social Council for Asia and the Pacific and others. RI has member organizations in 92 countries.

Mobility International USA (MIUSA) is a national non-profit organization working to improve opportunities for persons with disabilities in international education, leadership development, community service and travel. Since 1981, MIUSA has offered international exchange programs which include participants with and without disabilities in the U.S. and other countries. MIUSA exchanges specialize in leadership training, community service, cross-cultural experiential learning, and advocacy for the rights of persons with disabilities. Based in Oregon, MIUSA provides training and consultation and has published resource books, training manuals and videos, and curriculum guides to increase opportunities for persons with disabilities to be involved in international activities.

The IDEAS 2000 Project, founding sponsor of the International Leadership Forum, is a five year project funded by the U.S. National Institute for Disability and Rehabilitation Research, Department of Education, Grant #H133D40028.

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